An Investigative Study into the Current Understanding of Autism and Provision for Autistic Children in Kuwait

Being a Thesis Submitted for the Degree of Doctor of Philosophy.

In the University of Hull

By

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September 2000

Abstract

Autism is a severe form of childhood psychopathology which has enormous impact on the child, his/her family, and the wider community. It challenges the expertise of doctors, teachers and therapists.

In Kuwait, recognition of the disorder is still in its infancy. However, the government has established a new Centre for Autism, the first of its kind in the country, to provide up-to-date medical care and education for autistic children.

This investigative study attempts to assess the impact autistic children's behaviours have on their families within the context of Kuwait. This will be related to Kuwait's progress in catering for autism, in the light of current thinking world-wide. Autism is defined, early descriptions and theories as to aetiology are outlined, and the main trends of modern research are indicated. Within the context of the Review of Literature, distinguishing characteristics of autistic behaviour and the general impact upon families are identified and discussed, after which specific stresses and related problems are reviewed. Diagnosis and treatment are also considered. Discussion then turns to the roles of the main governmental and other bodies concerned with provision for autistic children in Kuwait, and an account is given of the special schools which are currently known to cater specifically for this disorder.

Because any medical condition, but particularly autism has an impact upon the immediate and extended family, information is also presented regarding coping strategies by Kuwaiti parents, as well as various therapies and training programmes and their claimed effects. Other factors influencing the family and which can cause

further stress, such as financial or health matters are similarly considered. All these elements are viewed in the light of the situation in Kuwait at the present time.

The evaluation of the impact on parents of the behaviour of autistic family members, was achieved by means of a questionnaire, *Survey Questionnaire of Families and their Responses to Behaviour Problems Related to Autism*, described in Chapter Six.

It is found that, in Kuwait, provision is limited and fragmented compared with the UK and the USA. This has resulted in families having to cope as best they can with the behaviours of their autistic children, which in many cases has caused stress and related problems. Moreover, there is, as yet, relatively little information available to researchers, parents, or the general public in this regard. Accordingly, recommendations are made for both action and research, in order to raise the issues of stress and the family, as well as raise the profile of this disorder in Kuwait and extend provision.

To My Parents

For their patience, love and understanding

Acknowledgements

I would like to express my thanks to my supervisor, Peter Randall, for his help and assistance throughout this research work.

I am deeply indebted to the following people who opened their doors for me and made this research work possible: Dr. Hussain Al-Anizee; Mr. Adil Dashti; Mr. Zaid Abbas; The staff of the Kuwaitis' Association for Handicapped; The Staff of Kuwait Centre for Autism; The Staff and Administration of the Khalifa School; Miss Lulah Al-Qutami; Dr. Ghazi Al-Naji; Mrs. Hana Al-Msellam and especially Dr. Joyce I. Korczak Fields for her continued encouragement, support, language correction and guidance in using NU*DIST.

Finally, I would like to thank the following people for their much-appreciated moral support and encouragement during the preparation of this thesis: my wife, my children, my sisters; and my brothers.

CONTENTS

Abstract	i
Dedication	iii
Acknowledgements	iv
List of Tables	x
List of Figures	xii
CHAPTER ONE – Introduction	1
1.1 Background to the Study	1
1.2 Study Objectives	3
1.3 Organisation of Study	4
1.4 Clinical Definitions and Descriptions	5
1.5 Summary of the Chapter	14
CHAPTER TWO – Historical Background	15
2.1 Introduction	15
2.2 Early Description and Theories	15
2.2.1 Asperger's Syndrome	22
2.3 Modern Research Perspectives	30
2.3.1 Behavioural	30
2.3.2 Medical	42
2.3.2.1 Autism – evidence for an organic cause	43
2.3.3. Cognitive Developmental	46
2.3.3.1 Autism at the cognitive level	46
2.3.4 Criteria for theories of Autism: parsimony and primacy	63
2.3.5 Epidemiology	71
2.3.6 Resumé of problems of diagnosis	72
2.4 Summary of the Chapter	75
CHAPTER THREE – Literature Review: Impact of Autistic Children's Behaviour on their Families.	76
3.1 Introduction	76
3.2 The Behaviour of Autistic Children and their families.	76
3.2.1 Babyhood	77
3.2.2 Childhood	80
3.3 Diagnosis and Treatment	84

3.3.1 Clinician Advice and Support 85
3.3.2 Treatment Models 86
3.3.3 Extended Treatment Environment in School and Community 88
3.4 Impact upon Specific members of the Family and their Management of Stress 92
3.4.1 Impact on Family 92
3.4.2 Impact on Parents 93
3.4.3 Training 101
3.5 Applied Behaviour Analysis 103
3.6 Alternative Treatments 103
3.6.1 Drug and vitamin therapy 103
3.6.2 Higashi 104
3.6.3 Option Method 105
3.6.4 Behaviour modification - Lovaas 105
3.6.5 Sensory integration therapy 121
3.6.6. Auditory integration therapy 122
3.6.7 Family therapy/psychotherapy 122
3.7 Support from within the Extended Family 123
3.8 Summary of the Chapter 127

CHAPTER FOUR – Provision for Autistic Children in Kuwait 128
4.1 Introduction 128
4.2 Background 129
4.2.1 Background to Current Cultural Practices in Kuwaiti Family Life 130
4.3 Governmental and other Bodies Catering for Special Needs 137
4.3.1 Governmental Bodies 138
4.3.2 Non-governmental Agencies 140
4.4 Special Education for Autistic Children 141
4.4.1 The Khalifa School for Children with Special Needs 142
4.4.2 Kuwait Centre for Autism 144
4.4.3 Montessori School 147
4.5 Summary of the Chapter 147

CHAPTER FIVE The Nature and Aims of the Field Study 149
5.1 Introduction 149
5.2 Rationale 149
5.3 Statement of the Problem 151
5.4 Aims and Objectives 151

5.5 Research Design 151
5.5.1 Background 151
5.5.2 Ethical Issues 152
5.6 Scope and Limitations of the Study 153
5.6.1 Threats to the validity of the Study 153
5.6.2 Scope of the study 155
5.6.3 Significance of the Study 156
5.7 Summary of the Chapter 156

CHAPTER SIX Methodology 157
6.1 Introduction 157
6.2 Study Location 157
6.3 Time Scale 157
6.4 Sample 158
6.5 The Research Instrument 158
6.5.1 Questionnaire Construction Process 159
6.5.2 Validation and Refinements 160
6.5.3 Pilot Study 162
6.5.4 Record Keeping 163
6.5.5 The Independent Observer 164
6.6 The Main Fieldwork 166
6.6.1 Pre-Experimental Period 166
6.6.2 Experimental Period 166
6.6.3 Post-Experimental Period 167
6.7 Summary of the Chapter 171

CHAPTER SEVEN Presentation of the Findings 172
7.1 Introduction 172
7.2 Description of the Sample 173
7.2.1 Gender 173
7.2.2 Age 173
7.2.3 Area Category 175
7.2.4 Number of Siblings 176
7.2.5 Age of Siblings 178
7.2.6 Child Disorder 179
7.2.7 Medication 181
7.3 Analysis of Questionnaire Data 181
7.3.1 Child's Communication of Needs 181
7.3.2 Ability to perform self-care skills 183
7.4 Parental Assessment of Available Resources 185
7.5 Parental Assessment of Residential Facility Staff 186
7.6 Current Behaviour Problems 188

7.6.1 Quantitative analysis of behaviours 191
7.6.1.1 Aggression 194
7.6.1.2 Self Injury 195
7.6.1.3 Pica 196
7.6.1.4 Destruction of Property 196
7.6.1.5 Tantrums 196
7.6.1.6 Stereotypic or Self Stimulating Behaviour 197
7.6.1.7 Withdrawing Behaviours 197
7.6.1.8 Messiness 197
7.6.1.9 General Statements 198
7.6.1.10 Sources of Help with Child's Behaviour 207
7.6.1.11 Analysis of identified particular resources as being needed to address challenging behaviour 213
7.7 Analysis of tape recordings using NU*DIST 215
7.7.1 Patterns and Themes 216
7.8 Analysis of the Pilot Study 220
7.8.1 Description of the Sample 221
7.8.2 Gender 222
7.8.3 Age 222
7.8.4 Area Category 223
7.8.5 Number of Siblings 224
7.8.6 Age of Siblings 225
7.8.7 Child Disorder 226
7.8.8 Medication 228
7.8.9 Analysis of Questionnaire Data in the Pilot Study 228
7.8.9.1 Child's Communication of Needs 228
7.8.9.2 Ability to perform self-care skills 230
7.8.9.3 Parental Assessment of Available Resources in the Pilot Study 232
7.8.9.4 Parental Assessment of Residential Facility Staff in Pilot Study 233
7.8.9.5 Current Behaviour Problems in the Pilot Study 234
7.8.9.6 Sources of Help with Child's Behaviour in the Pilot Study 237
7.8.9.7 Analysis of identified particular resources as being needed to address challenging behaviour in the Pilot Study 238

7.9 Summary of the Chapter 239

CHAPTER EIGHT – Discussion of the Findings 242
8.1 Introduction 242
8.2 Discussion 242
8.2.1. Incidence of Autism 242
8.2.2 Quality and Quantity of Provision and Funding 247
8.2.3 Academic Research in Kuwait 250
8.2.4 Comparison between the Western world and the findings in Kuwait. 253
8.2.5 Criticism of Parental Questionnaires 263
8.3 Summary of the Chapter 264

CHAPTER NINE – Recommendations and Conclusions 266
9.1 Introduction 266
9.2 Summary of the Research 266
9.3 Summary of Methods Used to Analyse the Finding 268
9.4 Recommendations 269
9.4.1 Home Based Programmes 271
9.4.1.1 Intervention 1: Behavioural Intervention (ABA) 'Lovaas Method' 271
9.4.1.2 Intervention 2: Options 273
9.4.2 School Based Programmes 274
9.4.2.1 Intervention 3: TEACCH 274
9.4.2.2 Intervention 4: PECS 276
9.5 Suggestions for Further Research 279
9.6 Weaknesses in this Study 282
9.7 Summary of the Chapter 284

Bibliography and References 285
Appendices 337
Appendix A: Diagnostic Criteria for Autistic Disorder from DSM-IV 338
Appendix B: The Code of Practice from the Education Act 1996 - United Kingdom 340

List of Tables

Table 2.1: Diagnostic criteria for Asperger's Syndrome suggested by Szatmari *et al* 1989. 24
Table 2.2: American Psychiatric Association DSM Systems for Diagnosis of Autism 30
Table 2.3: Differences between High Level Autism and Language Disorder 38
Table 2.4 Van Krevelen's distinguishing features of Asperger's Symdrome 47
Table 2.5: A Historical Line of Research into Autism. 69
Table 4.1 Number and Type of Children at The Khalifa School 142
Table 7.1 Age Distribution of Surveyed Family Members (N = 52) 174
Table 7.2 Descriptive Information on Family Member with Autism by Age Group (N = 52) 175
Table 7.3 Number of Siblings (N = 52) 177
Table 7.4 Age of Siblings 178
Table 7.5 Child Disorder 179
Table 7.6 Child's Communication of Needs 182
Table 7.7 Ability to Perform Self-Care Skills Unaided 184
Table 7.8 Current Behaviour Problems (N = 47) 189
Table 7.9 A Table of Analysis of Behaviours By Identified Type 193
Table 7.10 Sources of Help with Child's Behaviour 208
Table 7.11 Descriptive Information on Family member with Autism by Age Group in the Pilot Study (N = 20) 221
Table 7.12 Age Distribution of Surveyed Family Members in the Pilot Study 222
Table 7.13 Number of Siblings in the Pilot Study 224
Table 7.14 Age of Siblings in the Pilot Study (N = 20) 225
Table 7.15 Child Disorder in the Pilot Study 226
Table 7.16 Child's Communication of Needs in the Pilot Study 229
Table 7.17 Ability to Perform Self-Care Skills Unaided in the Pilot Study 231

Table 7.18 Current Behaviour Problems (N = 20) in the Pilot Study 235
Table 7.19 Sources of Help with Child's Behaviour in the Pilot Study 237
Table 7.20 Weaknesses in the current provision 240

List of Figures

Figure 2.1 Morton and Frith's (1994) causal models of three types of disorder. 27
Figure 2.2 Incidence of difference types of brain abnormality in Steffenburg's (1991) sample. 45
Figure 2.3 A causal model of the theory of mind account of autism (Frith 1992) 51
Figure 2.4 Graph showing the predicted probability of passing theory of mind tasks by VMA, for normal young children and individuals with autism (Happé 1994). 66
Figure 2.5 Bishop's (1989) dimensional approach to differential diagnosis 68
Figure 6.1 Hierarchical tree showing how parents response attributes were coded using QSR NU*DIST N4 169
Figure 7.1 Frequency and percentage of Diagnosis 180
Figure 7.2 Responses in percentage to the method used to Communicate Needs 183
Figure 7.3 Responses in percentage to ability to perform self-care skills unaided 185
Figure 7.4 Parental assessment of available resources by categories 186
Figure 7.5 Parental assessment of resources Residential Facility Staff 187
Figure 7.6 Parental assessment of resources Residential Facility Staff 188
Figure 7.7 Current behaviour problems 191
Figure 7.8 Behaviour frequency in percentage 194
Figure 7.9 Percentage of total sample of parent respondents reporting frequency of Challenging Behaviour 200
Figure 7.10 Percentage of total sample of parent respondents reporting frequency of Challenging Behaviour 201
Figure 7.11 Percentage of parent respondents reporting frequency of Challenging Behaviour for preschool aged autistic children in sample (Birth to 4 years) 201
Figure 7.12 Percentage of parent respondents

reporting frequency of Challenging Behaviour for preschool aged autistic children in sample (Birth to 4 years) 202
Figure 7.13 Percentage of parent respondents reporting frequency of Challenging Behaviour for primary aged autistic children in sample (7-11 years) 203
Figure 7.14 Percentage of parent respondents reporting frequency of Challenging Behaviour for primary aged autistic children in sample (7-11 years) 204
Figure 7.15 Percentage of parent respondents reporting frequency of Challenging Behaviour for adolescent aged autistic members in sample (12-17 years) 204
Figure 7.16 Percentage of parent respondents reporting frequency of Challenging Behaviour for adolescent aged autistic members in sample (12-17 years) 205
Figure 7.17 Percentage of parent respondents reporting frequency of Challenging Behaviour for adult aged autistic members in sample (18+ years) 206
Figure 7.18 Percentage of parent respondents reporting frequency of Challenging Behaviour for adult aged autistic members in sample (18+ years) 207
Figure 7. 19 Percentage of total sample of parent respondents reporting various resources as being very helpful or not helpful 210
Figure 7. 20 Percentage of parent respondents reporting various resources as being very helpful or not helpful for the preschool age group (birth to 4 years) 210
Figure 7.21 Percentage of parent respondents reporting various resources as being very helpful or not helpful for the primary age group (8-11 years) 211

Figure 7.22 Percentage of parent respondents reporting various resources as being very helpful or not helpful for the adolescent group (12-17 years) 211
Figure 7.23 Percentage of parent respondents reporting various resources as being very helpful or not helpful for the adult group (18+ years) 212
Figure 7.24 Percentage of parent responses that identified particular resources as being needed to address children's challenging behaviour. 214
Figure 7.25 Frequency and Percentage of diagnosis in the Pilot Study 227
Figure 7.26 Responses in percentage to the method used to Communicate Needs in the Pilot Study 230
Figure 7.27 Responses in percentage to ability to perform self-care skills unaided in the Pilot Study and the Main Study 232
Figure 7.28 Parental assessment of available resources in the Pilot Study 233
Figure 7.29 Parental assessment of resources: Residential Facilities Staff in the Pilot Study 234
Figure 7.30 Parental responses to Behaviour Problems - Pilot Study compared with Main Study 236
Figure 7.31 Percentage of parent responses that identified particular resources as being needed to address children's challenging behaviour in the Pilot Study 238

Chapter One
INTRODUCTION

1.1. Background to the Study

The severe form of childhood psychopathology known as autism attracts considerable interest and attention, due to the unique behaviours characterising the syndrome, its' resistance to treatment, and its elusive aetiology. Autism has enormous impact on the child, his/her family, schools and the wider community, and presents a challenge to a broad range of professionals. As Aarons and Gittens (1998, p. xii) state

> The concept of a spectrum of autistic disorders is now established, as is the variability of the condition.....we became increasingly aware of many very able children and adults with autism, whose needs were not recognised because of their good cognitive skills and evident academic ability.....There is a particular poignancy about the diagnosis of autism. Typically, these children look so attractive and normal that it is al too easy to ignore or dismiss the signs and symptoms and concentrate instead on the singular, often curious skills of islets of ability which the children frequently display.

In the West, autism as a distinct entity was described as early as 1943, and considerable research has been directed towards (a) distinguishing autism from other disorders, (b) identifying its causes, and (c) proposing treatment models.

There have been some advances in knowledge concerning the impairments of psychological function underlying the autistic behaviour pattern. Accumulated evidence has indicated that certain organic conditions tend to be associated with autism, though the precise way in which those causes operate to produce the typical

behaviour pattern remains unknown. It has become clear that the methods of teaching and managing behaviour problems appropriate for autistic children are also helpful for the wider group who have autistic features, but not the full classic syndrome.

Special provision for autistic children has been available for some time. For example in the UK, the National Autistic Society, established in 1962, set up schools for autistic children. The Society provides an information service and has done much to promote awareness and understanding of autism. Government funded research in 1984 considered the position of able autistic people in society, while more recently, a project has been established at the Child Development Research Unit at the University of Nottingham to describe public, private and voluntary sector provision and to study in detail some of the methods used to address the problems of autism. Equally, importantly there has been a positive change of direction in the way autism is presented, which is more representative of the variability of the condition (Aarons and Gittens, 1999, p. xiii). Further, whereas in the past autism was presented as a discrete condition, it is now seen on a continuum, a line of variability from severely affected individuals to those whose difficulties are very mild or can be seen as being eccentric.

The situation in Kuwait, however, is very different. It is only recently that autism has been recognised, and until 1988, there was no specific provision for autistic children at all. Provision is still very limited, and there is a great shortage of information. This may, at least in part, be due to attitudes prevailing in the society as a whole to all forms of disorder and handicap, which make autism a very sensitive issue. Equally, there is no specific specialist training in Special Educational Needs *per se* available in Kuwait at this time. Where there are individual units within programmes of study these are very elementary and sparse. So it would be accurate to

state that such units are almost negligible in comparison to the in-depth programmes of study available in Western higher education institutions and teacher training programmes.

As part of the endeavour to keep abreast of international developments in medicine and education, and to provide for the social welfare of Kuwait citizens, the government has set up a new Centre for Autism, the first of its kind in the country, and only the second in the Middle East as a whole (the first being an experimental unit set up in Jeddah, Saudi Arabia). It would seem, therefore, that this may be an appropriate time to review the current understanding of autism, to see how Kuwait is facing the challenge of coping with the disorder, and to consider the impact and effects this disorder has upon the immediate family and the extended family. It is hoped that this information will inform governmental agencies and private concerns within Kuwait on how they may develop provision and support in the future.

1.2. Study Objectives

As indicated above, the study of autism and provision for autistic children are new developments in Kuwait, and there is a need to assess the impact such a medical disorder has upon the immediate family, the extended family and the community in general. Accordingly, the specific objectives of the present study are as follows:

i To review the current understanding of the nature and causes of autis and how these impact upon the immediate family, the extended fam and the community at large.

ii To investigate within the context of this review of literature the identifi stress and related problems currently experienced by families of autis children in Kuwait.

iii To suggest ways in which provision for families of autistic children Kuwait can be supported through training and therapy to cope with t stress involved in dealing with the impact of autistic behaviours up them.

1.3. Organisation of the Study

The thesis is divided into nine chapters, as follows:

Chapter One outlines the context of the study and its objectives. Definitions of autism are also presented (see the next section).

The second chapter looks at autism from a historical perspective. Early descriptions and theories as to aetiology are outlined, and the main trends in modern research are reported.

In Chapter Three, an account is given, based on a review of literature, of the stress experienced by families whilst attempting to deal effectively with the distinguishing behavioural characteristics of autistic children. Approaches to coping strategies, and the various suggested training and therapy programmes and their related effects are reviewed.

Chapter Four turns to the situation with regard to autism in Kuwait. The roles of the main governmental and other bodies concerned with provision for autistic children are discussed, and an account is given of the only two special schools which are currently known to cater specifically for this disorder.

Chapter Five discusses the nature and aims of the empirical study carried out by the researcher, while Chapter Six outlines the methodology used in collecting and collating the raw data for this investigative study.

Chapter Seven describes the results of the investigative study related to the information and data acquired from the questionnaires and the interviews conducted in Kuwait to identify stress and related problems experienced by families of autistic children.

In Chapter Eight a discussion is presented of the findings, which are compared with those of the various studies detailed in the Review of Literature.

Finally, Chapter Nine offers recommendations for provision for Kuwait and suggestions for further research.

1.4 Clinical Definitions and Descriptions

The most commonly used current definition of *Autism* is that contained in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders DSM-IV (American Psychiatric Association, 1994). This is also the clinical criteria for diagnosis used in Kuwait and neighbouring countries and is, therefore, the criteria

used in defining the population of children diagnosed with autism in Kuwait that is sampled in this research.

This classification system of the American Psychiatric Association places autism in the category of "developmental disorders". This is group of disorders characterised by predominant disturbance in the acquisition of cognitive, language, motor, or social skills. Developmental disorders are easily confused with developmental disabilities, which federal legislation defines as including autism, mental retardation, cerebral palsy, and other disorders of the developmental period that have long-term effects on learning language, mobility, and self-care.

The American Psychiatric Association (1994) Diagnostic and Statistical Manual of Mental Disorders (4th Edition) states that a child reaches the diagnostic criteria for autism if the child evidences at least 6 items from the categories below, with at least 2 from the first category and 1 from each of the second and third categories. The child must evidence onset before the age of 3 years.

i. First category: Qualitative impairment in social interaction

- Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
- Failure to develop peer relationships appropriate to developmental level
- Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people
- Lack of social or emotional reciprocity.

ii. Second category: Qualitative impairments in communication

- Delay in, or total lack of, the development of spoken language in individuals with adequate speech
- In individuals with adequate speech, marked impairments in the ability to initiate or sustain a conversation with others
- Stereotyped and repetitive use of language or idiosyncratic language
- Lack of varied spontaneous make-believe (imaginative) play or social imitative play appropriate to developmental level.

iii. Third category: Restrictive, repetitive, and stereotyped patterns of behaviour, interests and activities

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- Apparently compulsive adherence to specific, non-functional routines or rituals
- Stereotypes and repetitive motor mannerisms (e.g. hand- or finger-flapping, complex whole body movements)
- Persistent preoccupations with parts of objects.

The other standardised classification system is produced by World Health Organisation (1993) and is called the *International Classification of Diseases* (ICD).

It is used exclusively throughout Europe and covers physical as well as psychiatric disorders. The latest edition is the tenth (ICD-10). The significant changes in both these classification systems help to demonstrate the changes in the perception of the changing nature of autism with age and ability and the continuing debate centred around diagnosis. It is recognised that the core deficits of autism remain despite significant variability associated with maturation and ability (APA, 1994).

It is important to remember, therefore, that autism is not an 'all or nothing' condition. The DSM-IV description recognises that different levels of severity exist such that the disorder is best conceptualised as a continuum ranging from mild to severe (American Psychiatric Association,1994). It can affect children across the whole spectrum of intellectual ability. The majority of pupils with autism will have additional learning difficulties, many of them resulting from global developmental delay. The autistic condition causes severe communication difficulties, regardless of the level of mechanical language ability. Many pupils with autism may also have specific language problems (e.g. Aaron & Gittens, 1999).Less commonly, there is an association with sensory loss and physical disability and a large number of children with autism suffer from epilepsy by the time they reach adolescence.

In contrast to this picture of multiple disability, there are some pupils who (at least on non-verbal tests) are functioning at an average or above average level of intelligence and may even have significantly advanced development in some skill areas. This means that pupils with autism are liable to be represented in all kinds of

school-both mainstream and special (e.g. Randall & Parker, 1999). They are even sometimes placed in schools for children with emotional and behavioural difficulties, either through mis-diagnosis or because their particular needs can best be met within that setting.

Amongst these are children with Asperger syndrome(APA,1994).

This syndrome was first described by the Austrian paediatrician Asperger in the mid-1930s. His original paper was lost for many years until found and translated relatively recently (Frith, 1989). As a result it has appeared for the first time in the last edition of the DSM series. There is unresolved controversy as to whether Asperger Syndrome is a separate disorder or merely a form of high functioning autism. Frith describes this elegantly by referring to people with Aspergers Syndrome a shaving "... a dash of autism" (Frith, 1989, p.8). Most clinicians pragmatically take this view when considering diagnosis (Randall & Parker,1999) and this is certainly the case for those children in Kuwait who makeup the sample studied. It is the personal opinion of this researcher that Asperger Syndrome is a high functioning variety of autism and is therefore at the upper end of the autistic continuum. For the sake of completeness the diagnostic criteria for Asperger's Syndrome given by DSM-IV is shown below. It can be seen that many of the core deficits are shared with autism but that there is a generally higher functioning level in respect of intellectual and language skills.

From DSM IV (page 77) the following diagnostic criteria are given for Asperger's syndrome :

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

B. (1) marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

C. (2) failure to develop peer relationships appropriate to developmental level

D. (3) a lack of spontaneous seeking to share enjoyment, interests, achievements with other people (e.g. by a lack of showing, bringing, or pointing our objects of interest to other people)

E. (4) lack of social or emotional reciprocity B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

F. (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

G. (2) apparently inflexible adherence to specific, non-functional routines or rituals

H. (3) stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)

I. (4) persistent preoccupation with parts of objects

J. C. The disturbance causes clinically significant impairments in social , occupational, or other important areas of functioning

K. D. There is no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by age 3 years)

L. E. There is no clinically significant delay in cognitive developmentor in the development of age-appropriate self-help skills, adaptive behaviour (other than social interaction), and curiosity about the environment in childhood

M. F. Criteria are not met for another specific Pervasive Developmental Disorder of Schizophrenia (APA, 1994, pp. 74-75)

It is often be difficult to make a differential diagnosis between autism and related conditions where the autism appears 'masked' by some more global learning problems. Also some children are said to have 'autistic features' rather than 'autism' and both parents and teachers can become confused about whether a particular child is included in these definitions (e.g. Randall & Gibb, 1999). In this thesis, pupils with autism are those with social and communication impairments out of keeping with their general mental abilities and who require a particular kind of education to take account of those impairments. In addition, they have a diagnosis in accordance with DSM-IV (APA, 1994).

It is also noted that younger and more severely impaired children with autism often show "associated features" including mental retardation, uneven cognitive skill development, abnormal postures and motor behaviour (e.g. stereotypics, such as arm flopping), unusual responses to sensory stimuli (e.g. ignoring pain or over-reacting to certain sounds), abnormalities of eating, drinking, sleeping or mood, and self-injury. Although other current definitions have different emphases, almost all highlight the importance of social and language deficits(e.g. Frith,1989).

Thus, Rutter (1978) identified impairments in social relationships and language development and insistence on sameness as the key features. Other groups studying autism have produced similar definitions that are still referred to(e.g. Creak, 1961;National Society for Autism Children,1978). In order to give the above definitions more clinical usefulness, several scales have been developed for use in identifying children with autism and measuring progress in their treatment. Parks (1983) reviewed five of these instruments, and recently Barthelemy *et al* (1990) introduced another. One of these scales is the Children Autism Rating Scale (CARS) the most recent version of which contains a useful comparison of the current definition of autism and their emphases upon different characteristics(Scholar et al, 1988) including impairment in imitation skills, disturbance in emotional response, peculiarities in use of body, inappropriate use of objectives, difficulty in adapting to change, unusual visual responses, unusual auditory responses, unusual use of response to taste, smell, or touch, unusual fears, impairment of verbal communication, impairment of non-verbal communication, abnormal activity level, unevenness in intellectual functioning, and onset prior to 30 months.

Special educational needs are defined by the interplay of a child's strengths and weaknesses within educational context. Because autism seldom appears as a child's only difficulty, and because of the wide range of ability found in autism, each child's needs will be very idiosyncratic. There are, of course, other multiply disabled children where this is equally true, but it is the variable and deviant developmental pattern found in autism that distinguishes it from other disorders. No matter what the delay, or at what point development stops, almost all other conditions follow a normal

developmental pathway. This is true of other disorders which produce uneven patterns of development across the skill areas. However, in autism this uneven pattern occurs both between and within areas of development.

For example, in language development, for most children the ability to communicate in a spoken language follows months of the development of communication skills using gesture, body language, itonational babbling and appropriate use of eye gaze. A spoken language greatly increases the sophistication of the communication that can occur, but it is built on a foundation of early verbal communication skills (e.g. Developmental References). In autism, where spoken language can so patently outstrip the ability to communicate or to understand the communication of other, it is not that such children do not understand the language, as it seems that they may have a good understanding of the literal meaning of the words, but they do not understand what the speaker means. This leads to distressing misunderstandings of what is to occur. For example, when a young girl with autism was admitted to hospital, she recoiled in horror from the nurse's request that she should give her hand. The nurse wished to take her pulse. The patient thought she was about to have her hand amputated (Happé,1994).

So, whereas other children may be led astray in their thinking sometimes because they are trying to make 'human sense' out of some artificial test (e.g. they fail conservation tasks because they assume they would not have been asked the question about which line has 'more', unless the numbers had in fact been changed), children with autism do not have to learn to think about language alone. They do not need to

extract language from its communicative context since, for them, it never had such communicative meaning in the first instance (e.g. Frith,1989).

1.5 Summary of the Chapter

This chapter has outlined the background to the problems in Kuwait related to Autism. It details the objectives, the organisation of the study, and clarified the clinical definitions used in this study. This chapter has also introduced the criteria (DSM-IV; APA, 1994) which is that used in Kuwait to diagnose the children of the sample used. The criteria for Asperger's syndrome are considered also.

In order to place this investigative study in context, the following chapter will briefly outline the historical development of theories identifying and diagnosing autism, early descriptions and theories of aetiology and some of the main trends of modern research.

Chapter Two
HISTORICAL BACKGROUND

2.1. Introduction

Autism enjoys a rich and unusual history in terms of its conceptualisation as a distinct diagnostic entity and hypotheses as to aetiology. This chapter provides a brief outline of some of the key developments in understanding of the disorder up to the year 2000, and indicates some research perspectives which have attracted attention since the 1960s.

2.2. Early Descriptions and Theories

Although it was only in this century that the term *autism* was introduced, accounts of children with similar behaviour have been present for many generations. Schopler (1983) gave as examples, Romulus and Remus, who according to legend were the founders of Rome and the feral children, Kamala and Amala, found by the Reverend Singh in Midrapore, India in 1929: thus the odd behaviour associated with autism has been recognised in many different cultures.

> 'He wandered about smiling, making stereotyped movements with his fingers, crossing them about in the air. He shook his head from side to side, whispering or humming the same three-note tune. He spun with great pleasure anything he could seize upon to spin. When taken into a room, he completely disregarded the people and instantly went for objects, preferably those that could be spun. He angrily shoved away the hand that was in his way or the foot that stepped on one of his blocks....'
>
> (Kanner, 1943; reprinted in Kanner, 1973 p.3-5)

Many accounts of special education trace the beginnings of the field to the work of Itard and his student, Edward Seguin, when teaching Victor, the "Wild Boy of Aveyron" ((Itard, 1894/1962, quoted in Berkell, 1992). As stated above, Schopler drew attention to the uncritical acceptance in these early reports on the legends that the children had been raised by wolves. Such reports did little to clarify the origins of childhood psychopathology, but they did provide indications that very deviant social and language development in children was observed long before Kanner's descriptions.

Hence, autism is a relatively new diagnosis, although the disorder was recognised over fifty years ago, by Kanner (1943) and Asperger (1944) who were the first to formally give it a name. Kanner's (1943) use of the word autism reflected his emphasis on the social deficits of the disorder, which unfortunately became confused with the syndrome he described with schizophrenia. Characteristics of the children described by him have since been shown to be quite different from those of schizophrenia, because the children whom he observed and described in his paper - *Autistic disturbances of affective contact* , highlighted a set of characteristics viz:

i. Extreme autistic aloneness

An inability to develop relationships:- This means that an autistic child will have difficulty interacting with people and is likely to show more interest in objects than other human beings.

ii. Anxiously obsessive desire for the preservation of sameness

This describes the insistence shown by many autistic children on resisting changes in their surroundings and daily lives. Also, repetitive and stereotyped play; typically, the play of autistic children is very limited.

They tend to repeat the same activity and do not develop imaginative pretend play.

iii. Excellent rôte memory

Many autistic children show remarkable feats of memory and rote learning. Some autistic children have outstanding abilities in multiplication of numbers, drawing etc.

iv. Delayed echolalia

This is the repetition of words and phrases, which is very common in autistic children. Also, pronominal reversal is very evident. This means simply that the child substitutes "you" for "I". For example: Parent: "Do you want a biscuit?" Child: "You want a biscuit." Likewise, delay in the acquisition of language. Although some autistic children remain mute, others do acquire language, but almost invariably it appears considerably later than in children with normal development.

v. Over-sensitivity to stimuli

For example an unfamiliar loud noise, will result in an autistic child screaming continuously. Or when another child or adult is playing tickling or when an autistic child is encouraged to pet an animal, many go nearly hysterical. This results in them displaying almost uncontrollable behaviour, as if they had been forced to do something unreasonable and which they do not wish to do, such as putting their hands into a fire.

vi. Limitation in the variety of spontaneous activity

Autistic children do not spontaneously show imaginative play or any desire to explore and investigate new situations. Likewise, when presented with celebrations, such as birthday parties or Christmas, most autistic children fail to respond with excitement. In part, this has been attributed to non-communicative use of spoken language after it develops. In spite of having adequate words at their disposal, they have difficulty in using them in meaningful conversation.

vii. Good cognitive potentialities

Many autistic children display a great deal of potential for music, reading, numbers, art etc. Because of their normal physical appearance, this was the last feature which encouraged Kanner to believe that autistic children invariably had normal intelligence, an impression that has only comparatively recently been discounted.

viii. Highly intelligent families

There has been and is a belief that incidences of autistic children are only born to families where the mother and father are highly intelligent.

(Kanner, 1943, p. 237).

Kanner elaborated his definitions, outlined above, by stating that the children fitting the description outlined in (a) failed to relate to people normally and appeared to be happiest when left alone. This lack of social responsiveness appeared to Kanner to start very early in life. For example, an autistic infant fails to put out his/her arms to a parent to be picked up. Plus, once he/she has been picked up by an adult an autistic infant does not snuggle into the adult's body, which is the norm for infant behaviour.

Likewise, in (b) he stated that the children displayed extremely upset behaviour if their normal routines or surroundings were changed, e.g. wearing the same clothes every day; sitting in the same chair at the table, etc. Only once these familiar routines and surroundings were re-established did their extremely upset behaviour stop.

However, Kanner (1943) pointed out that, whereas in schizophrenia withdrawal is a retreat from a distressing world, those with autism show extreme aloneness from the very beginning of life. He noted that autistic children do not assume an anticipatory posture when picked up, and he described them as from the start "anxiously and tensely impervious to people" (p. 249). In Kanner's view, autistic people have not withdrawn from a difficult world, but rather are total strangers in it from the beginning. He also highlighted characteristics such as isolated play, unusual language traits, insistence on ritual behaviour, and resistance to change, all of which are cited as central traits today. Some of Kanner's conclusions, however, have since been disproved. For instance, he noted the absence of physical stigmata of the children in his sample, whereas more recent research (Olley, 1992) with larger samples has demonstrated that people with autism may also have other identifiable medical syndromes.

Kanner (1943), also, identified an ability to memorise large amounts of meaningless information, such as an encyclopaedia index. Based upon such children's severe learning difficulties or mental handicaps, this type of ability was seen as exceptional. Likewise, he identified the characteristic outlined in (d) above, whereby children were unable to communicate using words beyond their immediate needs. This echolalia was explained by Kanner as the reason for the most common habit of using a whole question as a request, such as 'Do you want a sweet?' when the true meaning was 'I want a sweet'. Many of the children he observed reacted strongly to certain noises, which would result in screaming behaviours etc. and strong reactions to objects which resulted

in feeding problems or food refusals. In regard to (e) above, Kanner felt that whilst the children's repetitious movements, or verbalisations and interests could be very limited, some of the children showed a good understanding and competency in completing jigsaw puzzles etc.

Because of the above, Kanner was of the opinion that the outstanding memory and dexterity shown reflected a superior intelligence, despite the fact that many of the children in his sample were considered to have severe learning difficulties. This led him to identify (f) Good cognitive potentialities, where children with autism usually look normal. (This strong impression of intelligence is often felt by parents and teachers, and a good memory in particular is tantalising because it makes one feel that a child with autism could succeed if only they would make an effort). Based upon this assumption, and on his restricted sample, Kanner remarked that all his cases had intellectual parents, who were socially cold. Hence, Kanner (1943) felt that 'these children have come into the world with innate inability to form the usual, biologically provided affective contact with people' (p. 10). Thus, a misconception was begun by Kanner that autism was caused by parental behaviour. He drew attention to the upper middle-class backgrounds and the cold manner of the parents in his sample, in dealing with their autistic children.

Based on this theme, Bettelheim (1967) suggested that autism was attributable mainly to the emotional coldness of parents, particularly mothers. Later, Bettelheim (1967) coined the 'refrigerator mother' theory, based on the idea that children become autistic as a maladaptive response to a threatening and unloving environment. As Rimland (1989) pointed out, Bettelheim's views were heavily influenced by his experience as a prisoner in a Nazi death camp. He went so far to suggest that autistic children had been mistreated by their mothers in about the same way in which Nazi concentration camp prisoners had been mistreated by their guards, leading to feelings of

hopelessness, despair, and apathy, and to withdrawal from contact with reality. Against psychogenic theories is the fact that cases of children who are mistreated to a horrifying degree and neglected almost entirely show that such a history does not give rise to autism (Clarke and Clarke, 1976).

Hence, Rimland (1964) and other writers of the 1960s played an important role in changing the prevailing psychoanalytic view of autism which had been popularised by Bettelheim. Rimland himself had an autistic son. Influenced by this experience, in 1964 he wrote "Early Infantile Autism: The syndrome and its Implications for a Neural Theory of Behaviour", in which he expounded his view that autism is not psychologically caused. He proposed instead a neurologically-based approach, which laid the foundation for modern biomedical research. Nevertheless, there have been revivals of theories suggesting a psychological cause for the disorder. Aarons and Gittens (1992) cite the claim of Tinbergen and Tinbergen in 1972, that autism is caused by a failure of the "bonding" process between mother and child. In general, however, the psychoanalytic approach has lost credibility, and more recent research has focused on behavioural, cognitive-development, and medical viewpoints.

The perpetuation of the mythical view of the autistic child as a latent genius has led to great distress for families and teachers unable to find the key to unlock the alleged genius. More recent research has consistently found that about 80% of people with autism function in the mentally retarded range of intellectual development (cf. National Society for Autistic Children, 1978). The remaining 20% show social, language, or other learning problems that seriously impair their adaptive behaviour. Kanner's belief in the intellectual potential of people with autism appears to have been mistaken.

Independent of Kanner, in 1944, an Austrian physician, Hans Asperger, published a dissertation concerning childhood 'autistic psychopathy'. However, his work remained relatively unknown until it was translated in 1991 by Frith. It is interesting to note that, independently from each other, both Kanner and Asperger used the word autism to describe the symptoms which they witnessed. The term 'autistic' originated with Bleuler (1908), who used the Greek word 'autos' meaning 'self', to describe the social withdrawal seen in adult schizophrenia. And then in 1911 Bleuler used the term to describe a withdrawal into fantasy in schizophrenia.

2.2.1 Asperger's syndrome

The term 'Asperger's syndrome' was first used by Wing (1981). She introduced this diagnosis in order to identify those very able autistic people who do not fit the Kanner stereotype outlined above. Her diagnostic criteria list is:

i. speech - no delay, but content odd, pedantic, stereotyped

ii. non-verbal communication - little facial expression, monotone voice, inappropriate gesture

iii. social interactions - not reciprocal, lacking empathy

iv. resistance to change - enjoys repetitive activities

v. motor co-ordination - gait and posture odd, gross movements clumsy, sometimes stereotypes

vi. skills and interests - good rote memory, circumscribed special interests.

Wing, also, reported that Asperger claimed that the incidence of autism is more frequent in males than females, and is rarely identified before the age of three years.

Most researchers have followed Wing's suggestions fairly closely in their diagnostic criteria for Asperger's syndrome. By the end of the 1980s, a consensus of agreement was reached, when Burd and Kerbeshian (1987) suggested five features of Asperger's syndrome:

i. speech - pedantic, stereotyped, aprosodic
ii. impaired non-verbal communication
iii. social interaction - peculiar, lacks empathy
iv. circumscribed interests - repetitive activities or savant skills
v. movements - clumsy or stereotyped

Szatmari *et al.* (1989) suggested the following criteria, which constituted the first attempt at systematic diagnosis. However, these criteria do not take account of underlying handicaps which may be compounding the diagnosis.

Table 2:1 Diagnostic criteria for Asperger's syndrome suggested by Szatmari *et al* (1989)

1. Solitary - two of:

no close friends
avoids others
no interest in making friends
a loner

2. Impaired social interaction - one of:

approached others only to have own needs met
clumsy social approach
one-sided responses to peers
difficulty sensing the feelings of others
detached from feelings of others

3. Impaired non-verbal communication - one of:

limited facial expression
unable to read emotion from facial expression
unable to give message with eyes
does not look at others
does not use hands to express self
gestures large and clumsy
comes too close to others

4. Odd speech - two of:

abnormal inflection
talks too much or too little
lack of cohesion in conversation
idiosyncratic use of words
repetitive patterns of speech

5. Does not meet DSM-III-R criteria for autistic disorder.

Asperger (1944) felt sure that the children he described were in a separate category from Kanner's children with early infantile autism, although he acknowledged that the two groups had much in common. The similarities between Kanner and Asperger are that they both believed that the social handicap in autism was innate (Kanner's description) or constitutional (Asperger's description), and persisted throughout the life of the autistic person. Both identified the autistic characteristics of poor eye contact, repetition and restricted word and/or movements, and a high resistance to change. Also, both reported the bizarre and skilled performance of one skill in some of their samples, such as an ability to produce accurate architectural drawings of buildings, having seen them only once. Lastly, Kanner and Asperger believed that many of the parents of their patients displayed similar traits, such as social withdrawal or incompetencies, obsessive delight in routine, and the pursuit of special interests to the exclusion of everything else.

Areas where they disagreed are in the child's language abilities. Kanner reported that as far as the communicative functions of speech were concerned, there was no fundamental difference between the eight speaking children and the three mute children in his sample, as none used language to convey meaning. Those patients who could speak only echoed that which they heard. Asperger, on the other hand, reported that in his case studies all spoke fluently with originality in language usage when telling fantastic stories. In the area of motor control and co-ordination Kanner (1943) reported fluency and dexterity in his patients, except for one who was clumsy. Several of the children were a little clumsy in their gait and gross motor movements, but all were very skilful in terms of fine muscle co-ordination. Asperger, on the other hand, reported that all his patients were extremely clumsy and had pronounced problems with gross co-ordination in sports activities, as well as fine motor skills, such as writing. Finally, the other area of disagreement between Kanner and Asperger is in learning abilities. Kanner believed that

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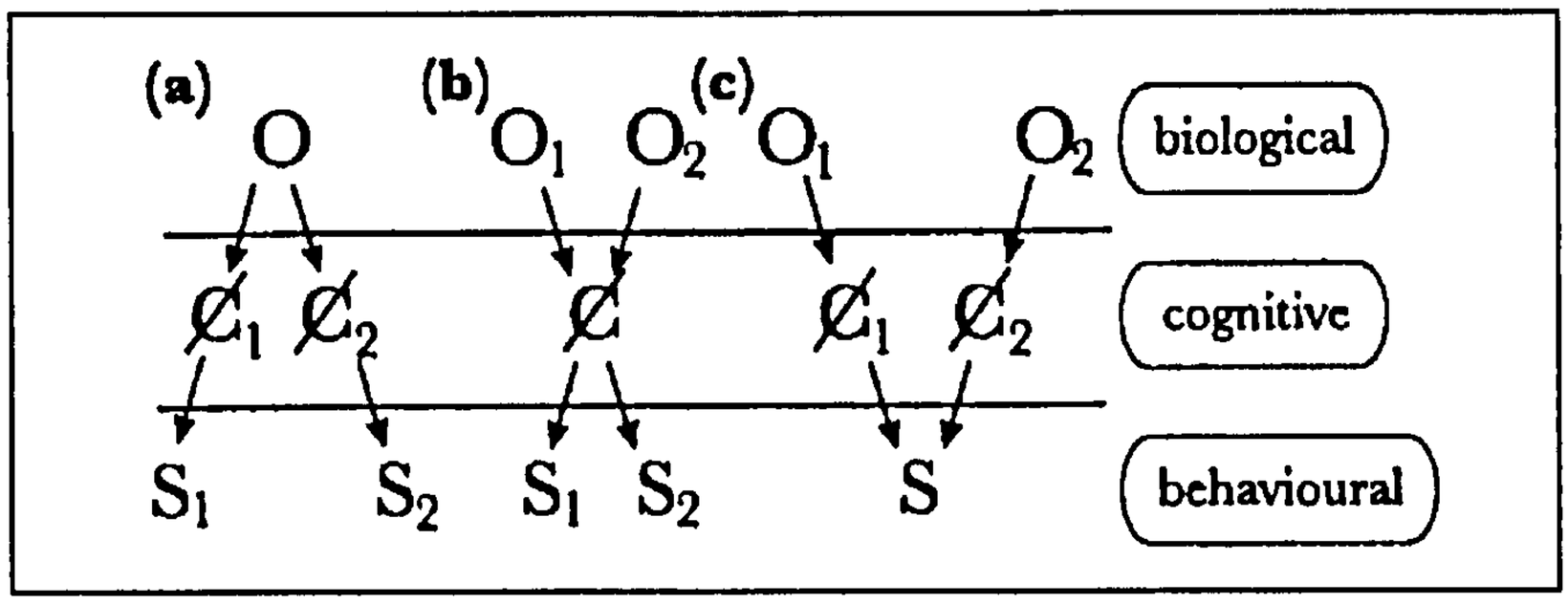
his patients responded best when learning by rote, whereas Asperger found that his patients produce their best work spontaneously.

Wing and Gould (1979) carried out an epidemiological study of children resident within a certain area of London. (See below for fuller description of this research). Within their study, any child with features of autism as well as all children with moderate to severe learning disability were included. From their results, they concluded that the core deficit in autism is *social* in nature. This means that a child with learning disability can be sociable relative to his/her mental age, whereas a child with autism, regardless of intellectual ability will have observable social impairments. These difficulties were described as *The Triad of Impairments of Social Interaction*: viz a. impairment of social relationships; b. impairment of social communication and c. impairment of social imagination.

Subsequently, Wing underlined the view that autism is on a continuum. Thus, Wing and Gould (1979) pointed out that the autistic person's problems may manifest themselves differently according to age and ability. This would suggest that there is a spectrum of behaviour which arises from similar underlying handicaps, and that whilst Kanner's clinical descriptions are primarily those used to identify autism, and seen today they conform exactly to the descriptions he gave, there is a danger of narrow stereotyping and of neglecting other facets. For example, an autistic person can display the characteristics but in a different form, such as no longer avoiding social interaction, but deliberately seeking it in an inappropriate manner. Therefore, the behavioural abnormalities seen in children with autism are less clearly linked with the level of social functioning detailed in *The Triad of Impairments of Social Interaction.*

Likewise, Morton and Frith (1994) have introduced a specific diagrammatic tool for thinking about the levels of explanation in developmental disorders such as autism. In the following figure, they show causal models of the three levels and the possible relationships between these levels, in different types of disorder. Pattern (a) is the case of a disorder defined by its unitary biological origin (O), which may have diverse effects at the cognitive and behavioural levels. Pattern (b) shows a disorder with multiple biological causes, and several different behavioural manifestations, but with a single defining cognitive deficit (C). Autism may be one such disorder. Pattern (c) is the case of a disorder defined only by its behavioural features (symptoms, S), with multiple biological causes and cognitive natures.

Figure 2:1 Morton and Frith's (1994) causal models of three types of disorder.



Similarly, as stated briefly above, the World Health Organisation (WHO) *International Classification of Diseases* (ICD) is widely adopted outside of the United States of America (USA). The ICD-8 places autism under the title of 'schizophrenia', thus, the final form of ICD-10 (1993) categorises autism as psychoses with an origin in childhood.

As detailed above, the American Psychiatric Association (1994) Diagnostic and Statistical Manual of Mental Disorders (4th Edition) states that a child reaches the diagnostic criteria for autism if the child evidences at least 6 items from the categories below, with at least 2 from the first category and 1 from each of the second and third categories. The child must evidence onset before the age of 3 years. The criteria are repeated here for convenience.

First category: Qualitative impairment in social interaction

- Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
- Failure to develop peer relationships appropriate to developmental level
- Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people
- Lack of social or emotional reciprocity.

Second category: Qualitative impairments in communication

- Delay in, or total lack of, the development of spoken language in individuals with adequate speech
- In individuals with adequate speech, marked impairments in the ability to initiate or sustain a conversation with others
- Stereotyped and repetitive use of language or idiosyncratic language
- Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level.

Third category: Restrictive, repetitive, and stereotyped patterns of behaviour, interests and activities

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- Apparently compulsive adherence to specific, non-functional routines or rituals
- Stereotypes and repetitive motor mannerisms (e.g. hand- or finger-flapping, complex whole body movements)
- Persistent preoccupations with parts of objects.

With the increase in knowledge and understanding of autism the DSM systems has changed, so in order to demonstrate and clarify the changes made to the DSM-IV (1994) in comparison to the DSM-III (1980; 1987) the following table details the different developments of diagnosis.

Table 2.2 American Psychiatric Association DSM Systems for Diagnosis of Autism.

	DSM-III (1980)	DSM-III (1987)	DSM-IV (1994)
Name of disorder	Infantile autism	Autistic disorder	Autistic disorder
Onset	Before 30 months.	During infancy or childhood.	Onset before 3 years of delayed or abnormal function in at least one of: social interaction, language for social communication, symbolic or imaginative play.
Social Behaviour	Pervasive lack of responses to other people.	Qualitative impairment in social interaction (5 mutually exclusive criteria).	Qualitative impairment in social interaction (at least 2 of 4 criteria).
Language and Communication	Gross deficits in language development. Speech, if present. has peculiar patterns.	Qualitative impairments in verbal and non-verbal communication and in imaginative activity.	Qualitative impairments in communication (at least 1 of 4 possible criteria).
Activities and Interests	Bizarre response to various aspects of the environment.	Markedly restricted repertoire of activities and interests.	Restricted repetitive and stereotyped patterns of behaviour, interests and activities (at least 1 of 4 possible criteria).
Exclusion Criteria	Absence of delusions, hallucinations, loosening of association and incoherence, as seen in schizophrenia.	None stated.	Rett's Disorder; Childhood Disintegrative Disorder; Asperger's Syndrome.

2.3. Modern Research Perspectives

2.3.1. Behavioural

Beginning in the 1960s, researchers applied psychological research from the laboratory to the learning of children with autism. Today the integration of basic behavioural research

and treatment programmes in many settings has led to substantial knowledge and improved support services. Early studies on the effects of rewards and punishments have led to a much broader emphasis on teaching practical skills for community living throughout the life span of the autistic person (Horner *et al*, 1988; Smith, 1989; Strain *et al*, 1986).

For Kanner (1943), the essential and defining symptoms of autism were the child's autistic aloneness and obsessive desire for the preservation of sameness. Any disorder will have core features which a person must show to receive the diagnosis. The starting point for progress in discovering the nature and cause of autism was built on a wealth of epidemiological and clinical data which showed that some symptoms displayed by some children with autism, are not symptoms of autism itself. Kanner's original description of autism has been modified over time with the recognition that the same handicap may be manifest in a number of different ways. Some children with autism avoid social contact, others are merely passive, or are even actively sociable in a peculiar fashion (cf. Wing and Gould, 1979; Aarons and Gittens, 1999).

Wing (1988) introduced the concept of a spectrum of disorders in autism in order to capture the idea of a range of manifestations of the same handicap. As stated above, Wing and Gould (1979) conducted an epidemiological survey of all children living in the Camberwell area of south London. The children were observed and given medical and psychological tests, and their carers were interviewed with the Handicap, Behaviour and Skills Schedule (Wing and Gould 1979). Abnormal speech was shown by 75 per cent of those with social impairment, versus 14 per cent of those showing social interaction appropriate for their mental age. Problems of socialisation, communication and imagination were found to be specific as well as universal to autism. Similarly, the person with autism may run away from social approaches, or may seem cut off and

passive, or may even pester people with questions and monologues, but according to Wing (1988) these behaviours all demonstrate a fundamental lack of social understanding.

In addition to these core features, which all children and adults diagnosed to have autism show, there are other characteristics which are typical but not universal to autism. For example, there can be striking discrepancies on batteries of intelligence tests where non-verbal ability (jigsaw-type tests) is often far in excess of verbal skills (cf. Lockyer and Rutter, 1969). Likewise, 1 in 10 subjects with autism display so-called savant abilities in music, drawing or mental calculations well in advance of their IQ (cf Rimland and Hill, 1984).

The set of three core impairments, which has become known as Wing's triad, is the basis for the diagnosis of autism today (Rutter and Schopler, 1987). Diagnosis of autism in the major diagnostic instrument currently used by clinicians the DSM-IV (American Psychiatric Association, 1994), is based on three fundamental impairments which capture Wing's triad:

i. qualitative impairment in reciprocal social interaction
ii. qualitative impairment in verbal and non-verbal communication and in imaginative activity
iii. markedly restricted repertoire of activities and interests

(The full diagnostic criteria for autism in DSM-IV can be seen in the previous sub-section).

Aarons and Gittens (1999, p. 8-9) suggest that more detail on each of these areas is required in order to clarify points on the continuum suggested by Wing. In the following, the lower numbers describe more severely impaired children, whilst the more able children with autism may be identified by the descriptions listed in number 4 in each of the areas of Wing's Triad. Before listing these, it is acknowledged that the levels identified are arbitrary; therefore, when identification of the level of autism is made the child can be functioning at that moment in time at any point along the continuum.

A. Impairment of Social Relationships

1. Aloofness and indifference to others.
2. Accepting of social approaches by others (passive).
3. Makes social approaches to others which are one-sided, and may be to indulge strange and unusual interests, e.g. railway time-tables, the marks socks make on ankles etc.
4. Makes social contact, but lacks understanding of subtle rules of social behaviour.

B. Impairment of Social Communication

1. Absence of any desire to communicate with others.
2. Communication confined to the expression of needs only.
3. Makes factual comments, not part of a social exchange, and often irrelevant to the social context.
4. Talks a great deal, but regardless of response of listeners, and has difficulty in engaging in reciprocal conversation. {This can be very subtle indeed, especially in individuals who have had access to social skills training}.

C. Impairment of Social Imagination

1. Copying and pretend play are absent.
2. May copy the actions of others, with/without real understanding of their meaning and purpose (may bath doll, make pretend cups of tea for example).
3. Repetitive and stereotyped enacting of a role, but without variation or empathy, e.g. a T.V. character, or an object such as an aeroplane.
4. Awareness that things go on in the minds of others, but has few strategies to discover what these may be. (Minimally affected people appear to have ability to recognise others' feelings, but this is learnt rather than empathetic).

In conclusion, Aarons and Gittens (1998) state that the behavioural abnormalities seen in children with autism are less clearly linked with the above stated levels of social functioning.

Reliable diagnosis of autism is rare before the age of 3 or 4 years. This is primarily because the types of behaviours which are impaired in autism (according to the diagnostic criteria outlined above) do not emerge reliably in normal children until this age. Early indicator studies are of two major types: (a) retrospective and (b) prospective. Retrospective studies work backwards, looking at the developmental history of the patient. Such studies are open to criticism because the benefit of hindsight may be unreliable. In order to attempt to avoid unintentional bias, researchers look back at reports written for medical and school records. These records are not biased by subsequent outcomes, but they are often found to be scanty or do not detail information that would be of value to the researcher. Prospective studies are studies that allow the

researcher to decide which early behaviours to monitor, and are, therefore, free from hindsight. However, if a disorder of interest is rare, a large initial sample may be needed in order to ensure that some of the infants will later prove to have the condition.

An early indicator of autism is only useful if it is fairly specific and universal. The search for an early indicator of autism must, therefore, compare the early development of autistic children with the early development both of normal children and of children with severe learning difficulties, but who are not autistic. Not only were no obvious markers of autism identified by health visitors in the child's first year, in addition abnormalities in social-communicative development at 12 months did not necessarily put a child at risk for later problems of this type (Lister, 1992). A rather different approach has been taken by Johnson *et al* (1992), who looked back at the infant health screening records of children who were subsequently diagnosed as suffering from autism, and compared them with the records of children who grew up to have mild or moderate learning difficulties, but no autism.

Single case studies have been reported concerning children who, for one reason or another, were closely monitored in their early years, before autism was suspected (e.g. Sparling, 1991). Camcorder records are a good source of information about the early years of an autistic child's development (Adrien *et al*, 1991). Baron-Cohen *et al* (1992) overcame the problem of doing projective research with a rare disorder, by targeting a group of infants who were particularly likely to have autism. Since autism appears to have a genetic component, these researchers concentrated their work on siblings of children already diagnosed to have autism. They devised a screening schedule, the Checklist for Autism in Toddlers (CHAT), based on current theories of the behavioural and cognitive characteristics of autism. Bailey *et al* (1996) state that the results of a number of studies of identical and non-identical twins where one or both are affected by

autism have provided important information related to genetic factors. These genetic factors appear to indicate that autism is highly heritable, and that there is an autism 'phenotype', that applies to a range of social and cognitive abnormalities in individuals of normal intelligence, of a kind that is very similar in quality to those found in autism but very different in the degree of handicap. (See below - v. Aetiology of Autism sub-section c. *Genetic studies* for fuller details).

However, there has been considerable argument about what underlies the varied picture that autism presents. As Aarons and Gittens (1998) ask: Why does a child who has only a few of Kanner's features have autism? What has such a child in common with one more obviously and seriously impaired? Is there a common thread? What is the link? In attempting to answer some of these questions, Frith (1989) in her book *Autism: Explaining the Enigma*, states whilst it is very satisfactory to be able to relate years of clinical experience of assessing and working with numerous children with autism, her experimental work based on Premack's Theory of the Mind (Premack and Woodruff, 1978), which concerns the ability to attribute mental states with content to others – also known as 'mentalising', can be used to make sense of the apparent contradictions seen in children with autism. The Premack Principle states that a low frequency desirable behaviour can be increased by the reinforcer of being allowed to engage in a desired high frequency behaviour (Premack, 1959).

Equally, Frith (1989) describes a problem that people with autism have in processing information, which she refers to as an impairment of 'central coherence'. This is summed up in the final paragraph of her book cited above:

> To identify the core features we had to look below the surface of the symptoms. It was then that we could see the red thread that was running through the evidence. It is the inability to draw together information so as to

> derive coherent and meaningful ideas. There is a fault in the predisposition of the mind to make sense of the world. Just this particular fault in the mechanics of the mind can explain the essential features of autism. If we lose sight of this fault we lose sight of the overall pattern.

Baron-Cohen (1989); Baron-Cohen *et al* (1992) and Happé (1994) have expanded on Frith's investigations using Theory of the Mind. For example, Baron-Cohen (1989) and Happé (1994) have developed procedures that demonstrate the validity of Frith's ideas by describing the difficulties of able children with autism. Thus, able children were unable to appreciate what another person might be thinking about a third person. The term *mind blind* has been used to describe these difficulties. Aarons and Gittens (1999) state that many parents have found this term helpful in understanding the nature of their children's problems.

From this work Baron-Cohen *et al* (1992) developed the CHAT (Checklist for Autism in Toddlers) whilst Happé (1994) produced a series of stories to be used with able autistic children. Their responses demonstrated their idiosyncratic view of events and any difficulties in attributing mental states to others. Happé (1994) found that some individuals in her sample group, despite being able to interpret the stories correctly, nevertheless had difficulty in coping with the social demands of everyday life. (See sub-section 2.3 below for fuller details). Aarons and Gittens (1999) believe this conundrum can be explained by the complexities of real-life situations compared with contrived experimental settings.

They also detailed the differences between High Level Autism and Language Disorder as there was a need to clarify the differences between these, with semantic-pragmatic difficulties and true language delay/disorder. The following is the table Aarons and Gittens (1999, p. 67) devised for easy reference.

Table 2.3 Differences between High Level Autism and Language Disorder

Autism – high level (semantic-Pragmatic difficulties)	Language only
1 Speech and language acquired by 5 years of age, but was delayed. 2. Language acquisition does not follow linguistic rules, but rote learned echolalic patterns. 3. Articulartory difficulties are less common. 4. Echolalic patterns gradually expand (chunking) – may display skilled use of learnt language and situational speech (mitigated echolalia). 5.Good auditory memory likely. 6. Expression is in advance of comprehension. 7. Conversational impairment apparent (ie child is unable to maintain interactive communication). 8. Likely to talk about own interests. Topics may be odd, range of topics limited.	1. Language acquisition is delayed and deficits persist. 2. Expressive difficulties exceed difficulties with comprehension. 3. More likely to show dyspraxic elements (ie child has articulation difficulties). 4. Echolalia if present is more likely to be simple and transient. 5. More likely to make attempts to gain interest of others (sharing of interests not just attention seeking). 6. Behaviour generally immature 7. More likely to show an even profile apart from language. 8. Word finding and word order difficulties apparent – auditory memory skills are poor.

9. Talks at people rather than with people (ie does not appear aware of listener's state of mind).	9. Conversational difficulties due to the word finding and word order problems, not an inability to use language appropriately because of an underlying impairment.
10. Often diagnosed as 'language difficulties and behaviour problems'. Child may be considered to have emotional and behavioural difficulties (EBD). Underlying social impairment is not recognised – once it is seen, child makes better sense.	10. Social difficulties due to immaturity not underlying deviance.
11. May or may not be evidence of more overt autism in history NB: features of autism recede as child develops.	11. Likely to show reading Difficulties not hyperlexia.
12. Learns easily, but does not necessarily understand and use what is learnt.	12. Play may lack imagination and be immature.
13. An uneven profile of skills, and deficits. NB: Islets of ability.	13. Milestones may be delayed – may be gross motor difficulties.
14. May be hyperlexic but there may be dyslexia linked to physical clumsiness (latter associated with Asperger Syndrome).	14. Child is able to use alternative strategies to compensate for lack of spoken language.
15. Play invariably limited, but may impress initially.	15. Child able to form real friendships.
16. Uses communication primarily for own needs, interests etc.	
17. Physical milestones may be normal and gross motor skills may be good.	

Further, Sallows (2000) conducted a review of the existing educational interventions for children with autism as cited by Jordan and Jones (1999). He found that

Jordan *et al* obtained information through questionnaires sent to professionals and support groups, as well as a review of published literature and several studies still in progress. Sallows (2000) concluded that whilst there were valuable comparisons of most approaches there seemed to be also very little controlled research supporting the claims the various approaches made. From the returned questionnaires Jordan and Jones (1999) found that Local Education Authorities (LEAs) in the UK were most interested in the effectiveness of the Higashi School, Treatment and Education of Autistic and Related Communications Disabled Children (TEACCH), and the work of Lovaas.

However, Sallows (2000) concluded that although all of this information was presented and was seen as necessary for parents, LEAs and professionals to reach sound decisions as to which intervention programme to use, some of the information was not easily accessible. From Jordan's personal views, which are well documented in her earlier work Jordan and Powell (1995), she believes that the defining deficits in autism cannot be remediated, but only adapted to and accepted: 'There is no reason to suppose that the child with autism is able to benefit from...an early developmental curriculum...beyond the mechanical rote learning of skills, which will be unrelated to understanding and therefore difficult to generalise or extend' (Jordan and Powell, 1995, p. xi). Therefore, she is a strong advocate for the TEACCH programme. (see below at sub section 3.6.4 for fuller details). And whilst this is seen as being acceptable Sallows (2000) strongly felt the need to present what he terms as *accurate comparative information*. This was because he felt that some of the information recorded by Jordan and Powell (1995) could be misleading due to the fact that each study cited implemented different criteria for measuring increase and decrease of skills in autistic samples.

The main issues Sallows (2000) raised were that Lord and Schopler (1989, p. 491) noted that among all children in their study, children given the *Bayley Scales of Infant*

Development (1969 and 2nd edition, 1993) tests at pre-test and *Merrill-Palmer Scale of Mental Tests* (Stutsman, 1948) at post test scored 14 points higher. Whereas, children tested using the Merrill-Palmer Tests as pre- and post-tests, scored only 2.5 points higher. It seemed to Sallows (2000) that the Merrill-Palmer was overestimating the IQ of the sample by about 12 points. Thus, when the same test was used in pre-post testing, there was actually very little improvement. Interestingly, Lord and Schopler (1989) recognised this problem when interpreting their results. They noted that '...mean Bayley scores were consistently 10 or more points below Merrill-Palmer scores' (Lord and Schopler, 1989, p. 490). So they concluded that '...one likely sources of this variability, i.e. the seeming increase in IQ of young nonverbal children, is the difference between the Bayley and the performance tests, particularly the Merrill-Palmer'. (Lord and Schopler, 1989, p. 495).

Increases in nonverbal IQ reflect improvement in visual and motor skills, which as stated above are relative strengths of autistic children, and they are then the bases of the TEACCH programme. Further, Jordan and Jones (1998) describe a more recent study of 22 children in a behavioural classroom where half of this sample received TEACCH home programmes (Ozonoff and Cathcart, 1998). It was stated that after four months, the children receiving the TEACCH home programme showed greater increases in imitation, motor skills and non-verbal imitation. This supports the conclusions that the National Autistic Society (UK) (1997, p. 99) came to when it was noted that when skills are taught in a logical sequences, and that while tangile rewards are used initially, verbal praise accompanies all reinforcers so that tangible reinforcers can be faded over time. These prompts are gradually reduced, and peer integration can be addressed usually in the second and third year of treatment (p. 100).

Jordan *et al* (1998, p. 115) also noted that while aversives were once part of the programme, they are no longer used. Thus, although Lovaas' dramatic findings were

once questioned, Jordan et al (1998, p. 114) note that more recently, researchers, such as Harris, Handelman, Gordon, Kristoff and Fuentes (1991) and Mundy (1993) felt that large and long lasting IQ gains are actually quite possible with intensive intervention during pre-school years. Summarising, Jordan *et al* state that the goal of the Lovaas programme is full inclusion in normal educational settings: 'The programme emphasises teaching in small steps, rewarding, giving clear instructions, prompting and fading, and teaching all the steps needed to enable participation in a normal nursery school where taught social skills are generalised' (Jordan *et al*, 1998, p. 99).

A fuller discussion of these findings will be conducted in sub section 3.6.4. The above serves to indicate that there is much controversy around many of the claimed results for intervention educational programmes with autistic children. And whilst, this is true, it is important to state that in the researcher's opinion it is not possible to simply wait until such controversies are resolved before attempting to help and support parents with autistic family members. Although, some intervention programmes may have flaws in them or in their reported findings, attempts to support parents and the autistic family member must be made and adjusted as and when new and substantiated research findings become available. It is unlikely that there will ever be only one programme which will address the educational needs of all autistic family members. It is more likely to be a combination of numerous intervention programmes and theories that proves to be effective in addressing the needs of such persons.

2.3.2. Medical

Recent medical research has increased our understanding of the neuroanatomical aspect of autism. For example, Dawson (1989) states that neurochemically, genetic abnormalities are found to be present in autism, as well as the effects of some of the medicines that can be used to treat some of the symptoms. Recent studies of the

autopsied brains of people with autism have found abnormalities in the limbic system and the cerebellum, which are areas known to be linked to memory and emotion (Bauman, 1990). Likewise, physical disorders associated with autism include maternal rubella, infantile spasms and untreated phenylketonuria. In addition, autism is also linked to known inherited disorders such as tuberous sclerosis, neurofibromatosis and fragile-X syndrome (Aarons and Gittens, 1992).

2.3.2.1. Autism - evidence for an organic cause

Reviews of the biological evidence of autism conclude that an organic cause is overwhelming (Gillberg and Coleman, 1992; Schopler and Mesibov, 1987; Gillberg, 1991). For example, Steffenberg (1991), found that almost 90 per cent of her sample of 35 autistic and 17 autistic-like children had evidence of brain damage or dysfunction (see Figure 2.2, which demonstrates the relative incidence of different sorts of brain abnormalities which were found in her sample).

Whereas, Aarons and Gittens (1999) report that for some time certain physical disorders have been known to be associated with autism. These include maternal rubella, infantile spams and untreated phenylkentonuria. Further autism is also linked to genetic disorders such as tuberous sclerosis, neurofibromatosis, fragile X-syndrome, and Rett's symdrome. Some children known to Aarons and Gittens (1999) have apparently developed autism after a mild dose of chickenpox. Their surveyed sample size was 100.

Further, they state that *candida albicans*, a common yeast-like fungus causing thrush, has been linked with autism. A significant number of parents reported unexplained high temperatures or transient rashes in their autistic children. Others reported that the immunisation programme, and in particular the measles component of

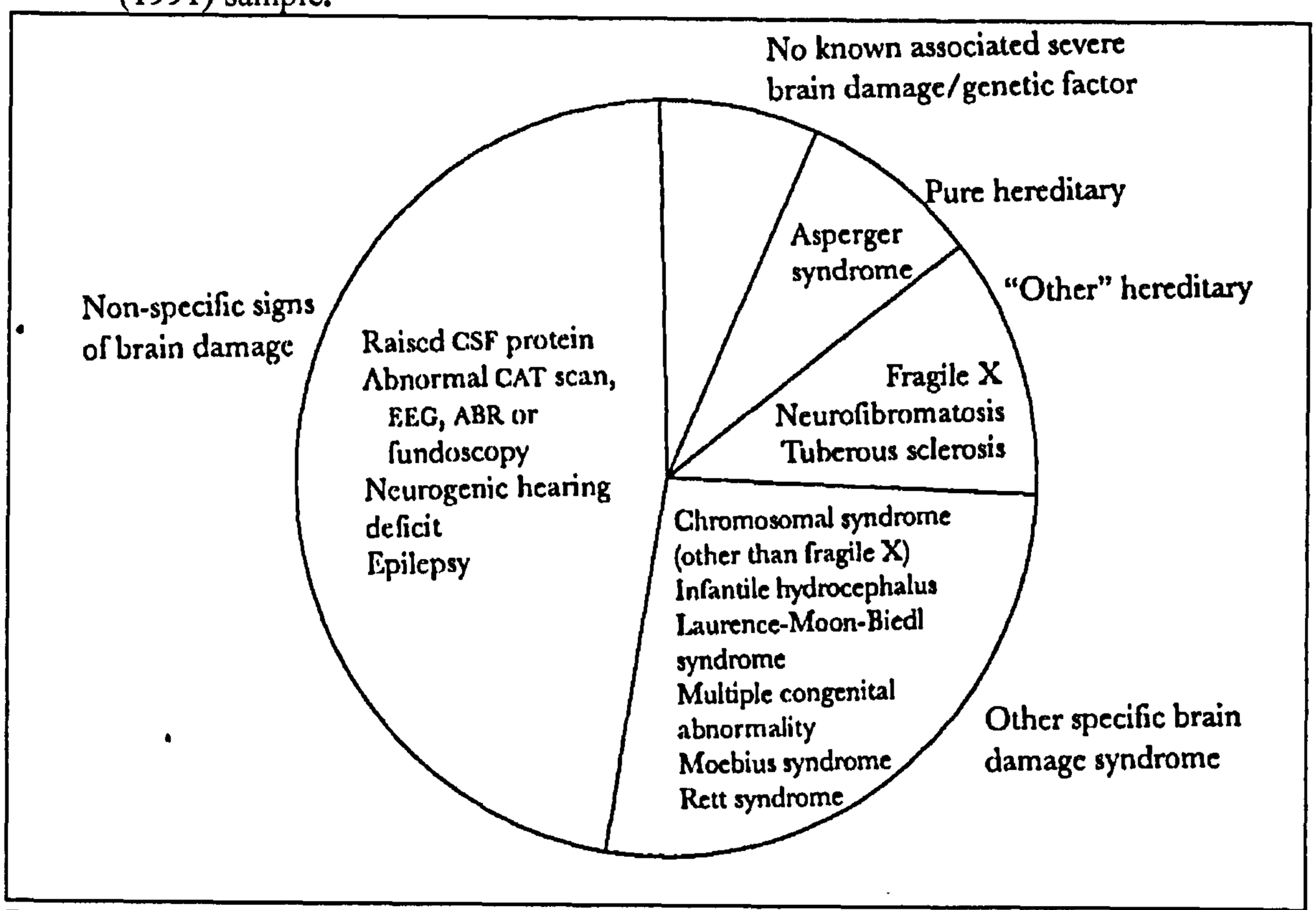
the MMR vaccine, has been blamed by these parents for the apparent increase of autism. Other factors, such as pre-natal scanning, technological approaches to childbirth, and environmental pollutants, along with a history of allergies of various types are cited by parents as causing autism.

Wolff (1988) attempts to summarise all the diverse aetiological factors associated with autism by saying that '..for autism to develop, brain damage has to occur in the setting of a genetic predisposition...the causation of autism which is likely to be heterogeneous, arises when a number of quite common factors coincide'. (Cited in Aarons and Gittens (1999, p. 19)).

It is important to note that one indication that brain damage is at the root of autism is offered by Olsson *et al* (1988). This is based on their results which collated the high incidence of epilepsy in autistic children. Whilst there are no unambiguous and universal findings that suggest the site of such damage, Steffenburg and Gillberg (1990) are confident that autism has a primary cause at the level of the brain. Unfortunately, no agreement has yet emerged concerning the critical area of pathway of the brain which is damaged in autism. Localising higher cognitive functions, such as social, communication and imagination skills impaired in autism, at the present time is, therefore, problematic.

Also, to compound these findings, Smalley *et al.* (1988) found that around three quarters of all diagnosed autistic people are generally mentally disabled. This fact in itself presents further problems of identification and accurate diagnosis when patients have an IQ level below 70. Likewise, the lower the IQ, the higher the incidence of autism.

Figure 2:2 Incidence of different types of brain abnormality in Steffenberg's (1991) sample.



Legend
ABR = Auditory brainstem response; CAT = Computerised axial tomography; CSF = Cerebrospional fluid; EEG = Electroencephalogram

Also, there is evidence for a genetic component in autism in the study of Rutter *et al.* (1994) where the exact role of the child's genes and sex ratio in autism is suggestive. For example, there is a significant familial loading for autism: Smalley *et al* (1988) found that autism is 50 times more frequent in the siblings of autistic people than in the general population. August *et al.* (1981) found that siblings who were not themselves autistic did, however, show a significant increased incidence of other cognitive impairments, such as language disorders and social impairments. Likewise, Green *et al.* (1984) found that mothers of autistic children reported more problems during pregnancy and delivery than mothers of children who later developed schizophrenia. (See below for further details).

2.3.3. Cognitive-Developmental

The basic deficits in cognitive processing, such as language, social, and related learning, have been the focus of another contemporary approach to autism. Some writers, such as Rutter (1978), have identified cognitive deficits in language, abstraction, and sequencing as the primary deficit in autism. Others, such as Hobson (1989), have stressed problems in social relatedness and effect. These studies have in common an emphasis on deficits in understanding abstractions, particularly those governing social behaviour. After many years of research, Kanner and Eisenberg (1956) isolated two of the above characteristics as the key elements of autism: (a) extreme isolation and (b) the obsessive insistence on the preservation of sameness.

2.3.3.1 Autism at the cognitive level

On the cognitive-developmental level, Van Krevelen (1971) supports the idea of an Asperger syndrome based on the belief that autistic psychopathy and Kanner's autism are two entirely different nosological syndromes. The crucial difference, in Van Krevelen's view, is the child's attitude to others, i.e. autistic children act as if others do not exist, whilst children with Asperger's syndrome evade other people; such avoidance implies an admittance of existence. The following table outlines the distinctive features which distinguish Van Krevelen's theory from Asperger's syndrome.

Table 2:4: Van Krevelen's distinguishing features of Asperger's Syndrome

	Early Infantile Autism	Autistic Psychopathy
1.	Manifestation age: first month of life.	Manifestation age: third year or later.
2.	Child walks earlier than he speaks; speech is retarded or absent.	Child walks late, speaks earlier.
3.	Language does not attain the function of communication.	Language aims at communication.
4.	Eye contact: other people do not exist.	Eye contact: other people are evaded.
5.	The child lives in a world of his own	The child lives in our world in his own way
6.	Social prognosis is poor.	Social prognosis is rather good
7.	A psychotic process.	A personality trait.

The task faced by cognitive theories of autism is to explain the specific pattern of deficits and preserved abilities across these areas in autism, i.e. problems in socialisation, communication, and imagination.

i. Socialisation

Autistic children are not globally impaired in social functioning, as Shapiro and Brain (1981); and Sigman and Mundy (1994) showed that autistic children seemed to show attachment behaviours which were no different from those of other (non-autistic) children with severe learning difficulties. Dawson and McKissick (1984) found that autistic children knew about their physical identity; they were able to recognise themselves in a mirror. They were also found in the controlled studies designed by Ozonoff *et al* (1990)

and Smalley, Asarnow and Spence (1988) to have an equal ability to the control group to recognise the faces of others. There is disagreement as to the age at which social behaviours can be identified. As yet, autism is rarely reliably diagnosed before the age of 3 years. Thus, social behaviours which are identifiable in normally developing infants have not been explored in infants with autism. For example:

(i) Autistic children have an inability to share and direct attention - they do not have 'protodeclarative' pointing as described by Curcio (1978). Normal infants around 9-12 months will follow an adult's eye gaze and share their focus of attention. It has been found that autistic infants do not.

(ii) There is some evidence that new-born normal infants show primitive imitation ability such as opening their mouths to an open-mouthed adult who is making faces at them (Meltzoff and Moore (1977), Meltzoff (1988). Whereas Sigman and Ungerer (1984) and Hertzig *et al* (1989) have demonstrated that autistic infants have difficulties in copying such movements.

(iii) Field *et al.* (1982) demonstrated that the first evidence of sensitivity to affect responses such as to 'social referencing' in response to a new toy according to the mother's facial expression (disgust or fear versus smiling (cf. Hornik *et al* 1987), was impaired in autistic infants at 12 months of age. Likewise, a number of studies by Hobson (1986a, and 1986b) Hertzig *et al.* (1989); Macdonald *et al* (1989); Smalley and Asarnow (1990), suggest significant deficits in the recognition of emotion by autistic children. (These subjects tended to be aged 5 years or older, rather than infants).

ii. Communication

There is a very striking spectrum of the range of communication handicaps in autistic children. This ranges from totally mute and autistic children who do not even give a gesture to communicate, through to echolalic children who parrot whole sentences which appear to have no relationship to the context, through to Asperger's syndrome children. Researchers, such as Frith (1989); Tager-Flusberg (1996); Schopler and Mesibov (1982, 1987 and 1992) and Paul (1987) have identified some core manifestations of the autistic communication impairments as follows:

(i) delay or lack of development of speech without any compensating gesture
(ii) failure to respond to others' speech, e.g. the child does not respond to his own name
(iii) stereotyped and repetitive use of language
(iv) pronoun reversal, such as saying you for I
(v) idiosyncratic use of words, and appearance of neologisms
(vi) failure to initiate or sustain conversation normally
(vii) abnormalities of prosody - pitch, stress, intonation etc.
(viii) semantic or conceptual difficulties
(ix) abnormal non-verbal communication gestures or facial expressions
(x) what seems most deviant is the autistic child's use of language which may show over-literal interpretation e.g. 'stick your coat anywhere' - child asks for some glue

(Baltaxe, 1977).

iii. Imagination

Wulff (1985) found that autistic children showed a striking absence of spontaneous symbolic play. For example, a normal 2 year old will pretend that a cardboard box is a motor car; an autistic child who has even a much higher mental age, will simply throw or spin the box. He is of the opinion that pretend play seems to be replaced in autism by repetitive activities, which may become obsessional. For example, an autistic man learned the name of every type of carrot (around 50 different types), and when asked to identify various species was always 100 per cent correct. However, it is important to note that such interest is of a very narrow nature, e.g. he showed no particular interest in growing or eating carrots.

As stated above, one recent psychological theory which has aroused a great deal of interest in recent years is by Frith (1992), who suggested that the triad of behavioural handicaps in autism results from an impairment of the fundamental human ability to 'mind-read'. By this they mean that normal children, from around the age of 4 years, have an ability to understand that people have beliefs and desires about the world. To them, such mental understanding states, rather than the physical state of the world, determine human behaviour. This theory of mind suggests that autistic people have an inability to attribute independent mental states to oneself or to others, or to think about one's own thoughts, resulting in impairment in social, communicative and imaginative skills.

Figure 2:3: A causal model of the theory of mind account of autism (Frith, 1992)

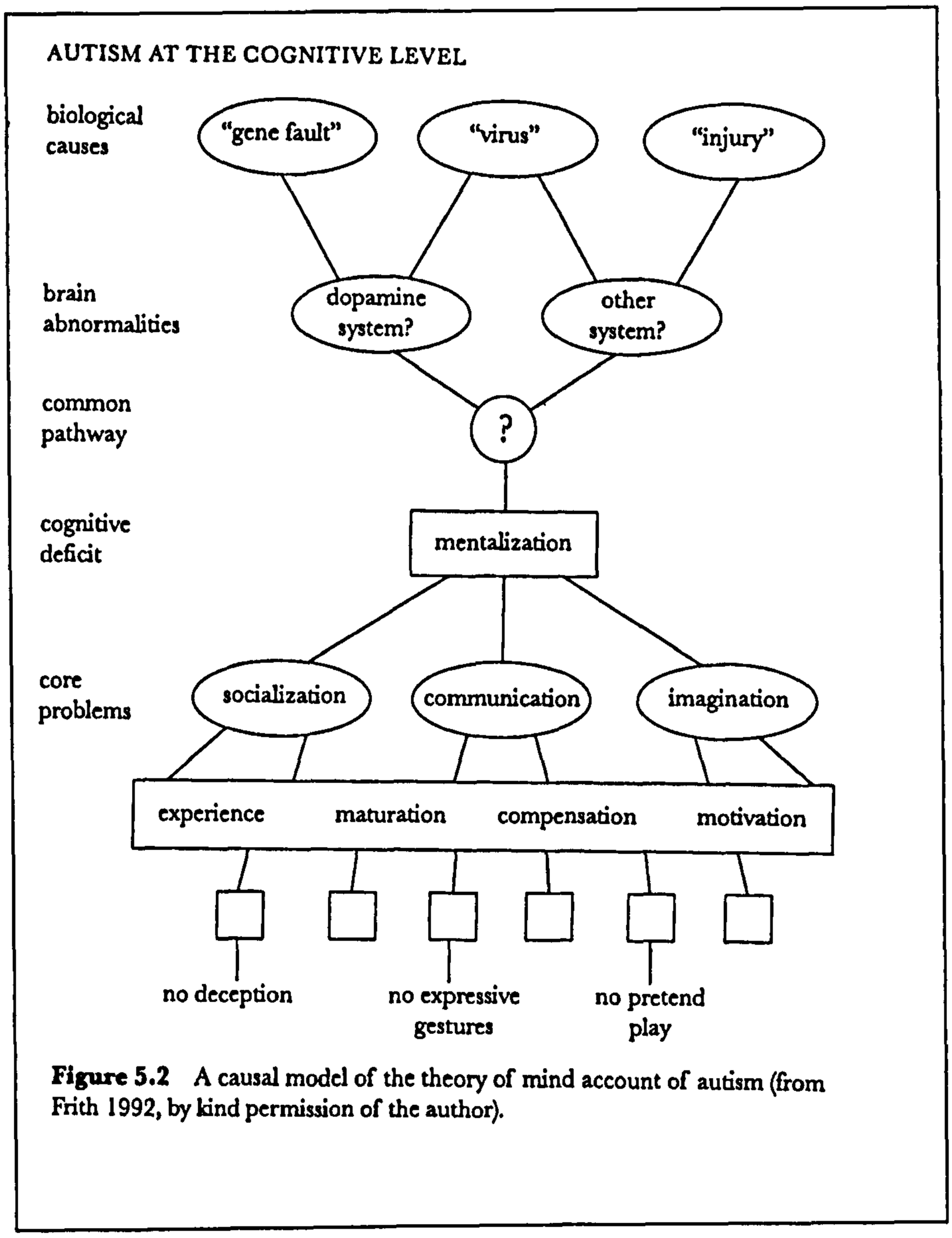


Figure 5.2 A causal model of the theory of mind account of autism (from Frith 1992, by kind permission of the author).

Happé (1993) raises the question of whether by using this theory of the mind one can 'get inside the mind' of a person with autism. She cites the following by way of example: Imagine yourself alone in a foreign land. As you step off the bus, the local

people crowd towards you, gesticulating and shouting. Their words sound like animal cries. Their gestures mean nothing to you. Your first instinct might be to fight, to push these intruders away from you; to fly away from their incomprehensible demands; or to freeze, to try to ignore the chaos around you' (p.49). The world of the person with autism may be rather like this, because the world is a social place. Not having the ability to make sense of others' behaviour must be terrifying - the world is unpredictable and the person isolated.

As stated above Aarons and Gittens (1999) believe that such a dilemma of conflicting evidence can be explained by the complexities of real-life situations compared with contrived more clearly stated experimental settings. One is constant, the other open to all the complexities and variation of everyday life.

iv Neuropsychological aspects of idiot savant phenomenon

> Neuropsychology is the field of study concerned with the relationship between behaviour and the mind on the one hand, and the nervous system, especially the brain, on the other.
>
> (Oxford English Dictionary, 1989, p.354).

The following is a brief resumé of some of the issues related to the *idiot savant* phenomenon. Steele, Gorman and Flexman (1984, p. 102) concluded from their research using a formal neurophychological test battery on a subject using 13 subtests that

> An idiot savant is most likely found in an autistic person with inhomogeous (scattered and selective, as opposed to general, damage uniformly affecting all areas of the brain) brain injury with preserved capacity for abstraction restricted to a single sphere of intellectual function.

Further, Ericsson and Faivre (1988) postulate that there are three main types of memory, viz.

- Ancestral, i.e. memory traits which tend to run in families
- Cognitive and associative, whereby experience in everyday life is processed and encoded, and involves recognition, retention and recall
- Habit, defined as a system of conditional reflexes, that enter the brain through the basal ganglia. It is an example of the classic stimulus-response model of behavioural psychology in contrast to the less automatic, conscious thought model of cognitive psychology.

Related to the *idiot savant* memory, Treffert (1989, p.185-186) believes that the memory displayed by most savants is of the habit type cited above.

> Savant memory, I suspect, is just that – a highly developed compensatory, non-cognitive, alternative pathway developed to compensate for injury to or absence of the more usual and more frequently used cognitive memory seen in the rest of us. Savant memory is almost devoid of emotion, is automatic and non-volitional, is certainly not reflective or highly associative.

In contrast, Ericsson and Faivre (1988) argue that unlike physical skills, mental skills can be performed in complete silence and in most environments. Thus, they further argue that it is in this repetition of processes, and not in memory alone, that is important for the development of idiot savant skills. O'Connor and Hermelin (1984), and Critchley and Henson (1979) agreed that memory was the most important factor in pursuing special abilities, though interest, perseverance and continual practice were also essential components. Moreover, Goodman (1972, p. 271) believes that *idiot savants* are unable to forget, rather than having an extraordinary ability to remember.

> The savant shows impressive long-term memory for what is usually short-term material for the rest of us; materials such as phone numbers or assorted

> other trivia. The insignificant facts remain and actually obscure or block pathways to more long-term, more typically associative memory.

The fact that the left hemisphere of the brain develops later than the right hemisphere in the foetus, and is therefore at greater risk from prenatal influences, may relate to autism and *idiot savant* in particular. This is because one of the prenatal influences is a male-related factor, probably circulation of testasterone, which is a hormone that can slow cortical growth and impair brain development in the left hemisphere. This results in enlargement of the right hemisphere, and a shift in dominance to this side of the brain. Thus, there are greater manifestations of right brain skills, the sort exhibited by idiot savants. The high number of male, as opposed to female, autistics can be explained by this theory.

Restak (1984) states that, regardless of the particular skill used, cognitive or symbolic factors determine which side of the brain is being used. The left hemisphere of the brain is related more to functions that use sequential, logical, symbolic or abstract strategies, e.g. reading or speaking. The right hemisphere of the brain controls functions that use spontaneous, intuitive, non-verbal or concrete strategies, e.g. painting, sculpting or constructional activities. As Treffert (1989, p. 170) states, this links with the *idiot savant* memory, which is characteristically non-symbolic.

> The predilection for simultaneous, high-fidelity non-symbolic, literal skills and functions, is reflected in the cortical migration and rededication, and in the unique neural circuitry of the memory....Once established, intense concentration, practice, compensatory drives and reinforcement play a major role in developing and polishing the savant skills and memory made possible by this unique brain dysfunction.

With the current development of new technology for the study of the brain, research will gain a deeper insight into why and how *idiot savants*' skills develop, thus perhaps offering answers to questions such as why do *idiot savants* choose their particular area of repetitious interest? If certain stimuli were changed, would that result in

a difference choice of repetitious interest? Should savant skills be trained and developed at the cost of other skills, e.g. social, communication?

v. Aetiology of Autism

Research into the aetiology of autism has had a late start but the progress in this field has been very rapid. It would appear that autism is a clinically heterogeneous disorder that has yet to be explained by variation in etiological factors. Autism, from neurological, neurochemical and genetic studies is mainly biologically determined, and the environment has little or any impact on its development. Whilst many of the findings are only preliminary they appear to be relevant and some are interlinked. For example, genetics are related to neurochemical and neurodevelopmental abnormalities, as well as problems during pregnancy and birth.

Because autism has been classified as a pervasive developmental disorder (PDD), with abnormalities in verbal and non-verbal communication and social interaction, Mackowiak (2000) conducted a literature review concerning the biology of autism. She states that research into biological factors are seen as the main underlying causes of autism, and these are focused on four areas: neurological, biochemical and genetic abnormalities, and problems during pregnancy and/or birth. A brief resume of these will be given below. Mackowiak concludes that a long list of potential factors implies that autism is a heterogeneous disorder, and to date there is no unified model that would explain its aetiology.

The following is a brief resumé of Mackowiak's findings.

a. Neurological and neuroanatomical studies

Schreibman (1988) reports that one third of autistic individuals develop epilepsy and that the majority suffer some level of mental retardation has in itself been suggestive of brain abnormality. This supports the findings of Bradshaw and Mattingley (1995) who state that autism is frequently found to coexist with other diseases or syndromes affecting

the central nervous system (CNS), including mental retardation. Tuberous sclerosis, neurofibromatosis, epilepsy, congenital rubella, fragile X-syndrome, Rett syndrome, Down syndrome, Williams syndrome, Jubert syndrome (with cerebella dysfunction) and moebius syndrome are all associated with autistic symptoms, suggesting that several d ifferent brain areas, perhaps forming a functional unit, could be targeted. Accordingly, Schopler and Mesibov (1987) undertook a number of studies to investigate possible brain abnormalities, because of finding problem areas at the level of the cerebellum, limbic system, and cortex. Further, Bauman & Kemper, (1994) demonstrate that there is evidence of defective brain lateralisation in some autistic individuals.

Recent neuroradiological studies, such as Hashimoto *et al* (1995), using magnetic resonance imaging (MRI), found that the brainstem (including the midbrain, pons and medulla oblongata) and the cerebellum were significantly smaller (and the fourth ventricle larger) in autistic patients. This finding is important as low levels of IQ may be related to the small size of the brainstem, especially the pons. Additionally, Courchesne, Press and Yeung-Courchesne (1993) argue that both the brainstem and cerebellum have connections with and affect the function of the limbic system and this area has been implicated in infantile autism. Hashimoto *et al* (1995) hypothesised that early damage to the midbrain and medulla oblongata could contribute to delayed development in autism; further, that a decrease in size for one area (i.e. medulla oblongata) is likely to be associated with loss of cellular material in another (i.e. cerebella vermian lobus).

This would somewhat explain why the cerebellum was found to be smaller in some autistic subjects. Their study concluded that the brainstem and vermian abnormalities were most likely a result of an early insult and hypoplasia rather than to a progressive degenerative process (Hashimoto *et al.*, 1995). Such findings as these and those of Bradshaw and Mattingley(1995) indicate that autism is not only a neurodevelopmental disorder but also a "secibd trunester syndrome". Secibd trunester sydrome is abnormal developments within the brainstem and cerebella vermian lobus. However, because recent post mortem studies did not detect lesions typical of prenatal brain damage (Bauman and Kemper, 1994), this suggests that there could be other processes involved in abnormal development of these areas.

Abnormal lateralisation has also been implicated in autism so Bradshaw and Mattingley (1995) speculate that such abnormalities could disrupt circuitry and function of the hippocampus and amygdala and the limbic and sensory association neocortex. Such abnormal lateralisation would possibly affect motivation, emotion, memory and learning, which are often seen as affected in autism. Further, Bradshaw and Mattingley (1995) cite their findings in animal studies, where lesions to the above mentioned brain areas were found to produce autistic like behaviour in monkeys.

Mackowiak (2000) suggests that perhaps there are various subtypes of autism that depend on different areas of damage to the brain. This would explain why there is such diversity in expression of the disorder. As stated above, in the past researchers had much difficulty with defining autism, mainly because none of the characteristic behaviours are

unique to the disorder. As a result DSM-IV (APA, 1994) introduced several non-autistic subtypes to allow for a broader conception of autism.

Further, Piven, Arndt, Bailey and Andreasen's (1996) recent post-morten findings indicate that autistic individuals tended to have larger heads than non-autistics. Support for this assertion may be found from Woodhouse, Bailey, Bolton, Baird, Le Couteur & Rutter, (1996), who reported an association with increased head circumference in their autistic sample. However, Rutter (1999) argues that there is some confusion as to how to interpret these findings, as researchers are unsure whether this is a result of a neurodevelopmental abnormality, or where it is a feature that is genetically determined. On-going research may eventually answer this question.

b. Neurochemical and neuropharmacological studies

Neurochemical and neuropharmacological studies have focused mainly on the dopaminergic and the serotonergic systems. However, Brodal (1981) states that in animal studies, disruptions to these systems had resulted in severe behavioural consequences, such as social withdrawal, as well as morpholgic consequences on the brain (Brenner, Mirmian, Uylings & Van der Gugten, 1983), that are similar to those seen in autism. Moreover, Cooper, Bloom and Roth (1978) stated that these systems were important to study, since they mainly arise in the brainstem and project into the limbic and cortical structures and the basal ganglia areas that have been implicated in autism.

Anderson (1994) studied the mesolimbic dopamine system and found that dopamine antagonist aggravated autistic behaviours, and that the dopomine agonists treated such behaviours. These results have led Anderson (1994) to suggest that they indicate that there could be an underlying problem in the dopaminergic brain stem and the mesolimbic pathways that project to the mesolimbic cortex. Such an assertion is supported by research done by Bradshaw and Mattingley (1995) who have found that there is some evidence that in autism there are problems in communication between these areas.

Studies have shown that abnormalities of temporal lobes may cause some linguistic and emotional deficits, which has led Bradshaw and Mattingley (1995) to suggest that autism is a neurodevelopmental disorder that could be related with some pregnancy and/or birth complications, whereas, a study by Bolton, Pickles, Murphy and Rutter (1998) found obsessive compulsive disorder (OCD) to be strongly associated with communication and social impairments. This relationship seems to suggest that there could be a serotonergic dysfunction, similar to that implicated in OCD.

According to Bradshaw and Mattingley (1995), there is now compelling evidence that abnormalities in the central nervous system (CNS) serotonin function could play a major role in the psychophysiology of autism. This is supported by Cook and Leventhal (1996) who have found that increased levels of whole blood and platelet serotonin and increased rate of platet serotonin transmission have been associated with obsessive symptoms and autism. Further support for this theory is offered by Cook, Corchesane,

Lord *et al* (1997) who provide evidence that there seems to be a relationship between autism and the serotonin transporter gene. Additionally, neuropharmacological studies by Cook *et al* (1997) have found that serotonin transporter gene, and that depletion of serotonin precursor tryptophan can aggravate autistic symptoms in some patients (Longhurst, Potenza & McDougle, 1997).

These findings inspired research into the possible role of neuroleptic fluvoxamine (Prozac) in significantly reduced aggression, maladaptive behaviour, obsessive compulsive symptoms and improved language use in autistic adults. However, Longhurst, Potenza & McDougle, (1997) strongly argue that although these findings have brought hope to many parents, researchers have warned that more studies need to be done before any drugs are prescribed.

c. *Genetic Studies*

The first compelling evidence that autism could be a genetic disorder came from Folstein & Rutter's (1977) study. They found that the concordance rate for autism among monozygotic (MZ) twins was 36%, or 82% for a broader spectrum of related cognitive or social abnormalities, much higher than zero concordance for autism and 10% for cognitive disorder in dyzygotic (DZ) twins. Bailey *et al* (1996) with related studies have supported this finding, because this difference in concordance rates between MZ and DZ twins indicates that autism is clearly under some degree of genetic control. Additionally, the family studies of Bolton, MacDonald, Pickles, Rios, Goode, Crowson, Bailey and Rutter (1996) found a rate of autism among siblings to problems of around 3%.

Mackowiak (2000) states that although this figure may seem low, it should be seen as significant and suggestive of a genetic component when considering the low prevalence rate. Fombonne (1997) found that prevalence of autism is on average reported between 0.7-15.5 per 10,000).

The mode of inheritance in autism is still unknown. Risch (1990) states that the differences between DZ and MZ twins, together with the marked fall off in loading between first and second degree relatives, is inconsistent with the action of a single gene. He goes on to state that for a mendelian model of inheritance, the recurrence risk for recessive disorders should be 25% for both siblings, and 50% in dominant disorders. However, Pickles, Bolton, MacDonald, Bailey, Le Couteur, Joran, Sim and Rutter (1995) found that this is not the case in autism. It appears that the mode of transmission could be very complex. It is more likely that a number of genes are involved and that these mutations may act independently as in genetic heterogeneity, or interact epistatically, or both.

A number of studies have identified candidate genes that could be involved in the psychophysiology of autism. For example, marked gender differences and other over representation of males in autism (4:1) have also suggested the involvement of the X-chromosome (Bailey *et al* 1995). A recent study by Hallmayer, Hebert, Spiker, Lotspeich, McMahon, Peterson, Nicholas, Pingree, Lin, Cavlli-Sforza, Risch and Ciaranello (1996) has excluded any moderate to strong gene effect causing autism on the X chromosome. Further, Lauritsen, Mors, Mortesen and Ewald's (1999) study reported a

possible involvement of chromosome 10, chromosome 7 and chromosome 12. Genes localised in chromosome 12 also include a serotonin receptor. The implications for these genetic variants in the aetiology of autism and possible subgroups of patients still await further study.

Cook, Lindgren, Leventhal, Courchesne, Lincoln, Shulman, Lord and Courchesne (1997) found, however, that paternal inheritance can also be significant and lead to a normal phenotype, whereas maternal inheritance leads to autism or atypical autism. Lauritsen *et al* (1999) state that there are other candidate genes implicated in autism, but these areas need further investigation.

Based on the brief outline above, Bolton and Rutter (1990) speculated that the finding that genetic factors may be involved in the majority of cases of autism could possibly contradict the evidence that autism is associated with pregnancy and birth complications. They argue, however, that the two findings do not have to be contradictory, by suggesting that obstetric complications might be an actual consequence rather than a cause of abnormality in the foetus. In contrast, Bradshaw and Mattingley (1995) argue that it is possible that maternal effects and/or pregnancy complications may interact with one or more susceptibility factors in the child. Mackowiak (2000) believes that both of these theories are feasible and in the light of these findings she states that it is fair to argue that autism may not be purely genetically determined, although heritability for autism has been calculated to be greater than 90% by Bailey *et al* (1995).

Thus, Mackowiak (2000) summarises by stating that, whilst in her opinion, research into the aetiology of autism has had a late start, the progress has been very rapid. It is now clear that autism is a clinically heterogeneous syndrome that has yet to be explained by variation in aetiological factors. The study of autism has been very difficult, as there is much variation in the autistic phenotype. Further, she says that because many of the abnormalities associated with autism are common to other disorders, the findings briefly outlined above are very promising and with continuing research, the prospects of defining a model that would explain autism aetiology are very bright.

2.3.4 Criteria for theories of autism: parsimony and primacy

According to Happé (1995), current theories of autism can be grouped under the following headings:

(i) those which claim that failure or false belief tasks do not reflect a lack of mentalising but rather some other impairment, or task artefact;

(ii) those which accept that failure or false belief tasks reflect a lack of mentalising, but deny that this is a primary, core psychological impairment on the basis of (i) lack of universality of this deficit and (ii) lack of causal precedence of this deficit.

Hughes and Russell (1993) have shown that on a number of non-social tasks, such as a computer version of the Tower of Hanoi, most children with autism did show some impairment when required to act away from the object. Russell *et al.* (1991) and Hughes and Russell (1993) offer an alternative psychological theory of autism, which focuses on

the child's inability to disengage from the object. They suggest that the autistic child is unable to do the above because of a specific difficulty to overcome, owing to the need for the object to be in 'real' location, as opposed to abstract location.

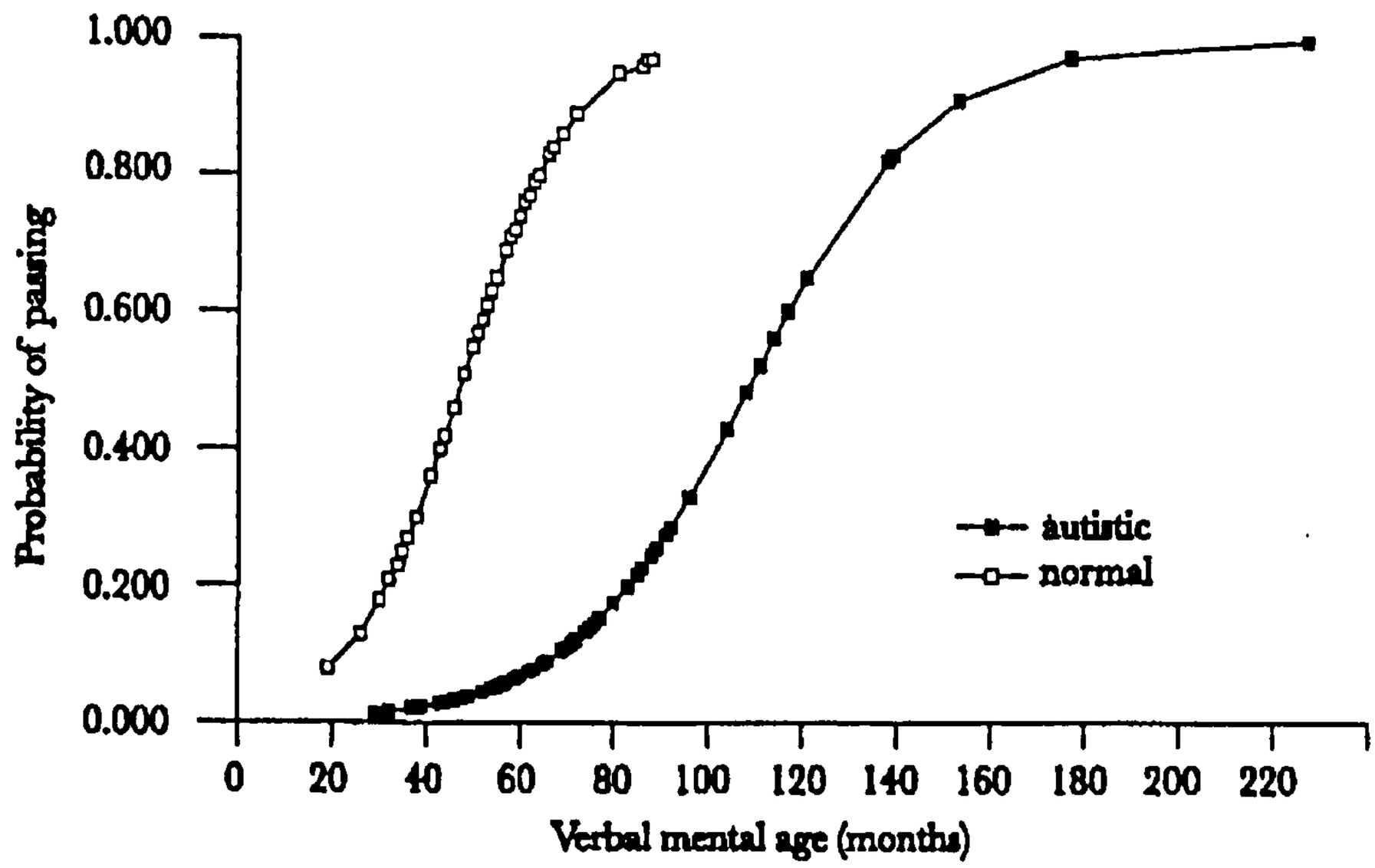
Even if some people with autism can think about thoughts, this does not rule out a causal role for mental problems in autistic development. A delay hypothesis (Baron-Cohen, 1989) suggests that it is easy to forget the importance of the normal development of children when considering the deficits in autism. Hobson (1989, 1990, 1993) maintains that such deficit is but one sequel of a much deeper impairment which prevents the child from establishing normal personal relationships. This is supported by Perner (1991) who suggests that the autistic child's lack of ability to build personal relationships may result from an early deficit which disrupted the child's ability to learn from normal social experiences. Recent psychological theories of autism have focused on the social impairment as the key feature of autism.

Szatmari *et al.* (1989) in their study compared high-functioning autistic subjects with Asperger's syndrome subjects against an outpatient control group on a number of tasks. They found that more mothers of high functioning autistic children than of Asperger's syndrome children reported that their child lacked social responsiveness, and showed no interest in social relations, showed echolalia, repetitive speech and stereotypical behaviour and showed no ability at imaginative play. A lack of any striking difference was also found in the study of the early histories and outcomes with these subject groups (Szatmari *et al*, 1989). They concluded that 'there were no substantive,

qualitative differences between the Asperger's syndrome and autistic groups, indicating that Asperger's syndrome should be considered a mild form of high functioning autism' (p. 94).

By contrast, however, Ozonoff *et al* (1991) concluded that in their study of the differences between an Asperger's syndrome group and a high functioning autistic group, an empirical distinction could be made. They found that both groups were impaired relative to the control groups on executive function tasks and emotion perception, but that only the high functioning autistic group showed significant impairments on theory of mind tasks and memory tasks.

Figure 2:4: Graph showing the predicted probability of passing theory of mind tasks by VMA, for normal young children and individuals with autism (Happé 1994)



It would seem that at the present time Asperger's syndrome is probably a term used for the needs of clinicians rather than researchers. The ICD-10 (World Health Organisation, 1993) seems to define autism as Asperger's syndrome without the language and cognitive impairments. This is because experimental work to date would seem to indicate that the Asperger's syndrome label is used to mark a sub-group of autism which is at the more able end of the spectrum in terms of social and communication handicaps.

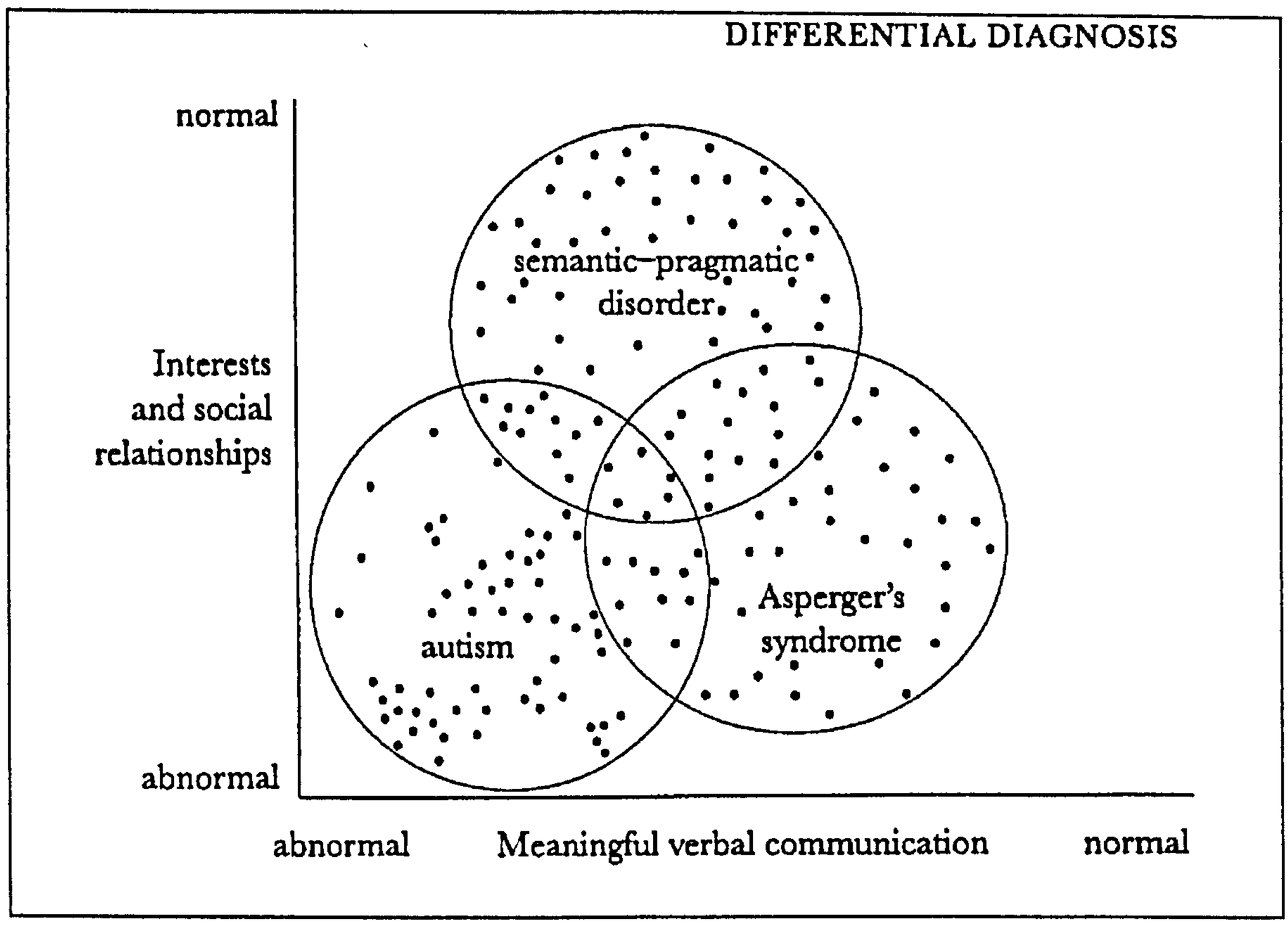
Autism appears in a great range of manifestations through a spectrum of disorders. Whereas autism is more easily recognised in individuals in the middle 50 percentiles of the normal distribution curve, the extremes are much more difficult to diagnose. This is because individuals' level of functioning at the 25 percentile and less is

so poor that social, communicative and imaginative functioning may be very low, or almost non-existent. At the higher 75 percentile and above level, autistic people may have devised their own coping strategies which in fact disguise their real problems.

Rapin and Allen (1983) discussed a semantic-pragmatic disorder, which became a popular diagnosis among speech therapists in the mid-1980s to describe children who showed comprehension problems, echolalia and verbal conceptual deficits. Although these symptoms are very similar to those found in autistic children and Asperger's syndrome children, Bishop and Adams (1989) suggested that a continuum approach should be taken. They suggested not just a single continuum of severity, but a two dimensional approach, in order to capture the differences in pattern of symptoms between the disorders outlined above. The following figure diagrammatically explains their theory (see Figure 2.5).

At the present time there is no cure for autism, although there are many treatments and therapies available. No drugs have been found which are effective in helping autism. At best drug treatments reduce anxiety and help to improve the social behaviour of such people. Behavioural therapies can have an enormous impact on individuals with autism, thereby reducing problem behaviour, teaching some skills and helping to maximise the innate potential of such people by concentrating on the things which they can achieve rather than attempting to develop skills a normal child possesses.

Figure 2.5: Bishop's (1989) dimensional approach to differential diagnosis.



As described above, the history of autism research can be summarised as having focused on the critical triad of impairments in socialisation, communication and imagination (Wing and Gould, 1979). Wing's triad had allowed researchers to think about social and communicative behaviour in a new way, so autism has come to be a test case for many theories of normal development (e.g. Sperber and Wilson 1986, Happé 1993). The following historical time line gives the development of such research.

Table 2.5: A Historical Line of Research into Autism

Assets	Deficits
1943	
Kanner	
1944	
Asperger	
1967	
memory for word strings (Hermelin & O'Connor)	memory for sentences
1969	
echoing nonsense (Aurnhammer-Frith)	echoing with repair
jigsaw by shape (Frith and Hermelin)	jigsaw by picture
1970ab	
pattern imposition (Frith)	pattern detection
1978	
recognising faces upside-down (Langdell)	recognising faces right way up
1984	
elicited structured play (Wetherby and Putting)	spontaneous pretend play
1986	
ordering behavioural pictures (Baron-Cohen *et al*)	ordering mentalistic pictures
1987	
sorting faces by accessories (Weeks and Hobson)	sorting faces by emotion
1988	
instrumental gestures (Attwood *et al*)	expressive gestures

1989	
understanding' see' (Perner *et al*)	understanding 'know'
1989c	
protoimperative pointing (Baron-Cohen)	protodeclarative pointings
1991	
memory for unrelated items (Tager-Flusberg)	memory for related items
1991/1992	
false photographs (Leekam & Pemer; Leslie & Thaiss)	false beliefs
1992	
sabotage (Sodian and Frith)	deception
object occlusion (Baron-Cohen)	information occlusion
1993	
talking about desires and emotions (Tager-Flusberg)	talking about beliefs and ideas
literal expression (Happe)	metaphorical expression
using person as tool (Phillips)	using person as receiver of information
1994	
showing 'active' sociability (Frith *et al*)	showing 'interactive' sociability

(cited from Fields, 1995, p. 6 -unpublished lecture handout.)

Frith (1989) is of the opinion that both the assets and the deficits of autism come from a single cause at the cognitive level, so he proposed that autism is characterised by a specific imbalance in integration of information at different levels. The universal feature of human information processing has become disturbed in autism, and this has led to a lack of central coherence. Frith states that autistic subjects would be relatively good at tasks where attention to local information is advantageous, i.e. receiving food, but poor at tasks which require the recognition of global meaning. With its speculative link to cognitive style, rather than simple deficit, the central coherence hypothesis differs radically from other recent theories of autism. For instance, it draws into focus many features of autism which have been neglected in recent investigations of the autistic social handicap. And like other theories, the theory of central coherence will require a systematic programme of research to establish empirical data, before it can justifiably be called a theory which will form a useful framework for thinking about autism in the future.

2.3.5 Epidemiology

The recorded incidence of autism in the population depends crucially upon how it is diagnosed and defined. The incidence in most studies appears to be around 4-10 autistic children in every 10,000 live births. However, Wing and Gould (1979) reported an incidence of 21 per 10,000 for the triad of social, language and behavioural impairments in the Camberwell study. Gillberg *et al.* (1986) found similarly high rates of the triad and mental handicap in Swedish teenagers. Other studies report an incidence of around 10 per 10,000 (Bryson *et al*, 1988; Tanoue *et al*, 1988; Ciadella and Mamelle, 1989). These recent studies from America, Japan and France, respectively, suggest that autism is found throughout the world, and is not more common in any one society than in another. The

reported incidence of autism has increased in recent years. This is probably due to better information and a wider conception of autism.

All the epidemiological studies show a significantly greater number of boys than girls with autism. Male to female ratios vary from 2:1 (Ciadella and Mamelle, 1989) to almost 3:1 (Steffenberg and Gillberg, 1986). The sex ratio seems to vary with ability: most girls with autism are at the lower end of the ability range, while at the more able end (Asperger's syndrome) boys may outnumber girls 5:1 (Lord and Schopler, 1987b). Szatmari and Jones (1991) have suggested some possible reasons for the lower IQ of females with autism. For example, females may be more strongly affected by the autism gene or there may be genetic heterogeneity, with more mild forms of the disorder being X-chromosome linked and hence more common in boys.

Both Kanner (1943) and Asperger (1944) remarked on the intelligence and high social standing of the families of children with autism, and this has given rise to the idea that autism is more prevalent among the higher socio-economic classes. There is little support for such an idea. Of the many epidemiological and population-based studies of autism, only one to date (Lotter, 1966) has shown any evidence of a social class bias. A number of reports have suggested that the association with social class may be an artefact caused by the greater likelihood that a middle-class parent will be able to get their child seen by a specialist (Wing, 1980; Gillberg and Schaumann, 1982).

2.3.6 Resumé of problems of diagnosis

Aarons and Gittens (1999) report that considerable changes and developments have come about in understanding the nature of autism. This has resulted in the field of research being thwarted with problems of diagnosis. Researchers in this field are aware of the variability of this condition, and the considerable widening of diagnostic boundaries that

enable recognition of autism in many of its subtle forms. Thus, percentages cited and used authoritatively in the past whilst diagnosing cases as 'classic autism', 'autism with severe learning disability' and 'autism with higher levels of intellectual functioning' are now seen as unhelpful and meaningless.

In the early 1970s there was little appreciation of the importance of intellectual functioning in the development of children with autism. As stated above, it was believed that intensive educational intervention would 'break through the barrier of non-communication' and allow the child to develop normally. Treffert (1989) highlights the talents of some children with autism who otherwise have severe learning disabilities yet have extraordinary ability in music, art and calendrical skills (the ability to work out correctly dates of the month, year going backwards and forwards from the calendar).

Aarons and Gittens (1999) record that more children will be encompassed by less rigid diagnostic criteria when their quality of social functioning is considered rather than the presence or absence of specified aspects of behavioural traits. In the near future a new diagnostic tool called *The Diagnostic Interview for Social and Communication Disorders* (DISCO) will be published by the National Autistic Society. They go on to state that many professionals tend to regard autism as a rare condition and when making a diagnosis, especially in a one to one situation, tend to overlook autism in many able children with autism who respond well to adult attention. The National Autistic Society recommend observation of children with suspected autism in social settings as they are more likely to be identified among socially normal peers.

Equally, when parents are questioned about their child's development, their answers can be misleading owing to whether or not parents actually understand the terms used and whether the professional using them can really evaluate the answers given. For

example, the words 'joint attention', are fraught with difficulties through insufficient thoroughness in clarifying what the concepts are by parents and/or professionals. A child with autism may show joint attention whilst looking at favourite toys or books, but this example of joint attention observation is not qualitatively the same as responding actively and creatively to the interests of another person. Similarly, the question 'Can you have a conversation with your child?' produces a wide range of contradictory answers because of the difference of perception of what a conversation is. Thus, this thesis has sought to ask questions where ambiguity is lessened in order to attempt to obtain data which are not skewed. Further, it is important to state that once autism has been identified, there is a change of emphasis from the clinical to the educational needs, because autism does not require medication unless it is accompanied by other medical conditions, such as epilepsy.

Gagnon *et al* (1997) report that when autism is seen primarily as a language disorder with social difficulties, generally the child is referred back to the speech therapist, with the supposition that remediation of the language problem is all that is required. Parents appear to be willing accept that their child is suffering from a speech defect rather than autism. This is compounded with the fact that some Local Education Authorities (LEAs) are reluctant to recognise the disorder because it could lead to substantial additional educational provision.

Parents are entitled to know what is the matter with their child; this justifies providing a diagnosis. Further, a diagnosis is likely to result in better management and appropriate provision of interventions for the child, as well as access to support groups, services and state benefits. Through correct diagnosis school placement is likely to be more suitable and therefore more successful. As Aarons and Gittens (1999) argue, the diagnosis should be a *qualitative* evaluation of the child's functioning in a variety of

settings, rather than the presence or absence of particular identified features in clinical surroundings.

2.4 Summary of the Chapter

The diagnosis of autism is characterised by a relatively short but controversial history, since the syndrome was described as a distinct diagnostic entity by Kanner (1943). Kanner's original criteria have emerged almost unchanged from the diagnostic debate. Understanding of aetiology has, however, been more controversial. Early theories focused on parent-causation. More recently, the focus has shifted toward the identification of biological aetiologies, reflecting the prevailing attitude that this disorder could be identified organically, rather than being psychogenically based. At the same time, the emphasis on behavioural treatments reflects the results of a body of research supporting the effectiveness of interventions based on learning principles.

The next chapter will review the relevant literature pertaining to the research into the impact of the behaviour of autistic children upon their families, and more specifically on their parents.

Chapter Three
LITERATURE REVIEW: IMPACT OF AUTISTIC CHILDREN'S BEHAVIOUR ON THEIR FAMILIES

3.1. Introduction

This chapter summarises the main findings emerging from the literature regarding the behaviour of autistic children and its effects upon their families. Not all members of the autistic child's family will experience all the behaviour characteristics displayed by the autistic child, and some characteristics are present in other disorders also. Nonetheless, it is possible to identify a number of categories of stress and stress related problems associated with the deficit or abnormality that make up the spectrum of autistic behaviour.

Secondly, the intention of this chapter is to outline some issues relating to the management of the impact of autistic children's externalising behaviours upon their families. It is notable that the picture presented here is based on western literature, and basically refers to the experiences of families living in the UK and USA. However, this review will provide an interesting basis for comparison with the situation in Kuwait, to be described in the next chapter.

3.2. The Behaviour of Autistic Children and their Families

Each autistic child is an individual, and is different in many ways from other children with the same diagnosis. This is partly because as stated previously, the condition may be present in any degree varying from very mild to very severe, but also because each child has his/her own personality which somehow comes through despite his/her disabilities. It

is, therefore, only possible to give a very generalised description, and it should be recognised that few children have all the symptoms identified and acknowledged as being within the spectrum of autism. Also, change usually occurs as children grow older, resulting in some problems becoming less marked, and some disappearing altogether. Nevertheless, it is possible to identify a common behaviour pattern, especially among younger children and the impact this has upon the immediate family.

Also, it is important to state that what one set of parents or family relations will regard as a major problem, another set of parents or family relations will cope with and not regard it as a problem at all.

3.2.1 Babyhood

Some babies who later show signs of autism appear to develop normally for a while, and for a year or two their parents do not notice anything wrong (although careful questioning may reveal that the babies were very passive, showing little interest in their surroundings). Other babies give their parents cause for concern almost from birth. Feeding problems are fairly common and some of the babies do not suck well (Wing, 1980). Or, sleeping problems are very commonly reported by Aarons and Gittens (1999), who state that many children with autism seem to require very little sleep and parents report that nights are interrupted and the household disturbed for years on end, starting from the early months of babyhood.

The cases where there is obviously something wrong from birth seem to fall into two categories. The first type scream a great deal during both day and night, especially on waking from sleep, and cannot be comforted or soothed. The baby may be stiff and hard to cuddle, and may fight against everything, including being washed, dressed and

changed. Obviously, family members, especially the mother, become concerned and may begin to feel that their own actions are causing stress to the baby.

The second kind of autistic baby is placid and undemanding, content to lie quietly in his pram all day and may not cry, even for food (Wing, 1980; Aarons and Gittens, 1999). This type of child is less exhausting than the first, and less obviously worrying, but parents eventually become concerned when the child does not become active. A characteristic frequently remarked upon by mothers is the autistic baby's failure to lift up his arms or show any need or wish or anticipation of being picked up. When lifted up, such children do not snuggle down comfortably in their mother's arms, and if carried pig-a-back later on, do not grip the parent. Strong feelings of rejection and confusion for the mother as well as other members of the immediate family can develop. These rejection feelings can then be compounded by feelings of guilt, and in some extreme cases rejection by the parents. During such times the emotions of the family on being informed that the new member of the family has a debilitating disorder can have catastrophic results. Donenberg and Baker (1993) reporting on the impact of young children with externalising behaviours on their families found that within their sample specifically related to autism, a number of respondents were in denial. By this they meant that some members of the immediate family, and this included a number of mothers, initially refused to nurse the child for a period of time after being informed of its condition. The main reason given for such rejection and behavioural response by the mother was devastating feelings of guilt. That is, the mothers felt that their child's condition must be a direct result of some action they had done or failed to do during pregnancy.

Other symptoms of denial are found when parents and immediate families insist that there is nothing wrong with the child because it looks absolutely normal. They offer the explanation that some children develop later than others. Further, it is reported that

because some autistic babies spend long periods in obsessive behaviours, such as tapping the pram cover, rocking, or head-banging, various members of the family reported that they were embarrassed by the situation (Konstantaraes *et al* (1992)). This embarrassment, although perhaps minimal within the privacy of the family home, was too great for them outside the confines of the home. Thus, there was denial and refusal to be associated with the infant. For example, because of feelings of deep embarrassment and strong feelings of self-preservation that over-rode family loyalties, some siblings denied that the child was related to them (McHale *et al*, 1984). McHale *et al* also reported that autistic family members displayed fascination with lights, or with any object that shines and twinkles, or on the other hand, they showed no interest in the things which are normally of interest to a baby as he /she grows and develops. This resulted in siblings being most inventive in explaining this behaviour to their friends in order to cover up the reality of the situation. Similarly, as autistic babies show no curiosity at passers-by, animals, or traffic, as opposed to a normal baby who would have wanted to look at such things, point to them, and squeal in excitement, explanations of quiet, subdued personalities were frequently offered to explain away the autistic child's behaviour.

Faced with such lack of interest, parents may begin to fear their child is severely mentally retarded, but they usually reject this possibility because autistic babies generally follow a normal pattern of growth and motor development (e.g. sitting, walking). Where these milestones occur later than n
ormal, it is more commonly the case that the child has other handicaps as well as autism (Wing, 1980; Aarons and Gittens, 1999). Sometimes, mothers indicate that their baby smiled when tickled, cuddled or bounced up and down, but not when looking at someone's face. They may also remember that he/she did not bother to sit up, even though capable of doing so, apparently because he/she had little interest in his/her surroundings. Some autistic children stand up and walk round the furniture at the normal time of development, but appear unwilling to let go and walk without support until many months after the usual age these actions occur.

3.2.2. Childhood

According to Wing (1980) and Aarons and Gittens (1999), it is usually between the ages of two and five years that autistic behaviour is most clearly manifested. In cases

where the child has appeared normal from birth, a marked and rapid change of behaviour around this age may soon indicate to the parents that something is very wrong. Young autistic children, especially if there is no other handicap which might affect their appearance, seem to be physically healthy and are often unusually attractive. However, they do not look directly at other people, seeming to be aloof and unaffected by the world in general.

The review of literature reveals a number of typical behaviour characteristics, which reflect more fundamental underlying handicaps:

i. Deficits in social behaviour: It is generally agreed that the hallmark of autism is the existence of profound and pervasive deficits in social attachment and behaviour (Schreibman, 1988; Denkla, 1986; Aarons and Gittens, 1999). Rimland (1964) notes the active avoidance of normal eye contact. Passive acceptance, or actual intolerance of physical contact is frequently reported, though Howlin (1986) suggests this may be overplayed. Autistic children are described as "loners", whose failure to develop social attachment and behaviour is evident in their lack of peer contact and interactive play (Rutter, 1978; Aarons and Gittens, 1999). These children do engage in social behaviour of sorts, but often relate to people as "objects" and treat them accordingly (e.g. Rimland, 1964; Schreibman and Mills, 1983).

Further, because of the idiosyncratic nature of autism, other social problems which require careful management may occur. Some relate to the child's insistence on repeating particular activities, such as opening and shutting doors, or drawers; watching a favourite video; listening to a certain CD, or persistent and meaningless questioning over and over again (The National Society for Autistic Children, 1978).

ii. Speech and Language: According to Rutter (1978), approximately 50% of autistic children never develop functional speech. However, Aarons and Gittens (1999) dispute this finding by stating that many more autistic children are capable of developing functional speech, but may be hampered in so doing because of parent or family denial of their condition. They say that a figure of 85% or more is a more accurate representation.

Those who do speak show a number of abnormalities. Echolalia is common (Fay, 1969). This may take the form of immediate repetition of a verbal stimulus just heard, or there may be delayed echolalia, in which the child repeats a verbal stimulus heard some time in the past, so that the speech is contextually inappropriate (Carr *et al*, 1975). This is a characteristic of most infants during speech acquisition, but continuation after 3 or 4 years of age is considered to be pathological (Ricks and Wing, 1975). As stated previously, pronominal reversal is another distinctive characteristic of autism (Ricks and Wing, 1975; Rimland, 1964; Rutter, 1978; Davies, 1993; Howlin, 1997a).

Another frequently-reported characteristic is extreme literalness in comprehending and producing speech (Wing, 1976). Dysprosody

(mistakes in pitch, rhythm, inflection etc.), also characterises the speech of most speaking autistic children (Schreibman *et al*, 1986; Schreibman, 1988).

iii. Abnormalities in Response to the Physical Environment: Autistic children frequently under or over-react to sensory events. A child may appear oblivious of loud noises, yet cover his ears and scream in response to lesser stimuli. He/she may appear not to notice events in a visual environment, but be obsessed by, for example, patterns in floor tiles (Schreibman, 1988). Under-and over-responsiveness to touch, pain or temperature has been reported (Ritvo and Freeman, 1978). Schreibman *et al* (1986) have shown that autistic children are typically over-selective, responding to only a limited amount of the sensory information available. It has been suggested that this may explain the variability of response in autistic children, and their difficulty in learning new behaviours.

iv. Demand for Sameness in the Environment: Many autistic children display a demand for sameness in routine. They display limited and rigid play patterns (Rutter, 1978) and may develop ritualistic preoccupations (ibid), such as dressing and undressing themselves or dolls with which they are playing. Another example of this is insistence upon having the same plate, cup and fork and knife etc.

Eating habits and likes and dislikes are often extreme. For example, some autistic children may eat only a very limited range of foods or insist on eating and drinking only from certain plates and cups. Other refuse to eat or

eat very little, hence their waiflike appearance, whilst others may well be obese due to an insistence on a diet of burgers and chips.

v. Self-Stimulatory Behaviour: Repetitive, stereotyped behaviour that seems to serve no other function than to provide sensory feedback is often viewed as a defining characteristic of autism (Rimland, 1964). For example, an autistic child will spend hours placing a variety of shapes inside a box, whilst totally ignoring the need to match the shape with the cut out shapes on the top of the box.

Empirical investigations, such as Rincover, (1978), indicate that this behaviour interferes with the children's responsiveness to environmental input. Again, an example of this is whereby, no matter what ploys are used to re-direct or channel the child's attention, it is found that an autistic child will always revert back to the activity he was engaged in prior to the input by the adult to re-direct his attention. This can occur even after three or four hours, where a normal child would either have lost interest or would have forgotten what activity he/she was doing prior to the adults' re-directioning.

vi. Self-Injurious Behaviour: The most dramatic behavioural abnormality manifested by autistic children is self-injurious behaviour (SIB), such as head-banging and self-biting. The intensity of SIB, and hence, the damage inflicted, can range from slight to extremely severe (Schreibman, 1988). Bartak and Rutter (1973) reported that SIB was more common in mentally retarded autistic children than in those of normal intelligence.

vii. Affect: Autistic children often display flattened excessive or otherwise inappropriate effect (American Psychiatric Association, 1987). They may display irrational fears that seem to be related to the demand for sameness (Schreibman, 1988).

As stated in the previous chapter, according to Wing and Gould (1979), the core deficit is social, and is apparent in three main areas of functioning, described as "The Triad of Impairments of Social Interaction". These are:

- impairment of social relationships
- impairment of social communication
- impairment of social understanding and imagination.

All the behavioural characteristics described above may be interpreted as manifestations of these three basic impairments.

Perhaps one of the most difficult situations is when features of autism are misunderstood by well-meaning but ill-informed professionals, who at times interpret the child's difficulties as symptomatic of bad parenting skills. Many parents report that such incidents add to their existing sense of guilt. Some have reported that this has actually been the cause of the breakdown of their marriage or relationship.

3.3. Diagnosis and Treatment

Autistic children's handicaps are severe, affecting every aspect of daily life, and they are not usually outgrown, though there is a tendency towards slow improvement. Although there is no known cure for these handicaps, this does not mean that the autistic child cannot be helped. Special methods of education, at home and school, can be used to help these children overcome some of their difficulties. In this sense, a comparison may be

made with the situation faced by the parents and teachers of a sensory impaired child. It may not be possible to cure the deafness or blindness, but the children can be taught to maximise whatever skills they do possess. Some autistic children have so many additional handicaps that they cannot make much progress, but nonetheless, it is worth trying to improve the worst behaviour problems and to teach simple self-care. Hence, some important aspects of education and management are outlined below, with an indication of approaches to provision for autistic children in the UK and the USA.

3.3.1. Clinician Advice and Support

Before anything else, the doctor must make sure of the diagnosis. He will consider information about the child's past history and behaviour and assess to what extent this fits the pattern of early childhood autism. He should then investigate the possibility that the child has any of a number of conditions which can be mistaken for autism, in particular that the child is not deaf, or visually impaired. The next step is to consider whether the child has any associated handicaps. These might be abnormalities of the brain and nervous system, such as spasticity or fits, or he might have some other physical problem which adds to his difficulties. Doctors have to be especially careful in assessing these extra handicaps, because the child cannot complain for him/herself and his/her odd behaviour might hide symptoms and signs that would be obvious in normal child. This diagnostic process takes time, as well as trust and co-operation between the doctor, his colleagues, and the family. Equally importantly, when autism is diagnosed it is essential to reassure parents that they are not the cause of the condition.

Other important rôles of the clinician include treatment of additional handicaps, alleviation of secondary behaviour problems (e.g. by prescribing medication for sleeplessness) and supporting parents through the emotional stress of dealing with an

autistic child, plus, the recommendation of help, advice and counselling, especially so when parents begin to realise that their child has a disability with lifelong implications. Because parents are not made absolutely clear about the condition of autism, some are attracted to unsubstantiated treatment programmes, such as swimming with dolphins, sound and light therapy etc. Hence, it is essential that as soon as the diagnoses are made, practitioners should provide good quality support immediately. Aarons and Gittens (1999, p. 53) reported that they have been surprised '..by the strength of feeling in parents who assert that they would rather live with false hopes of a cure for the condition of autism than accept what we could call a realistic appraisal of the situation'.

They see coming to terms with the diagnosis as in effect, coming to terms with the loss of a child through bereavement and learning to contemplate a future for their child and themselves which is different from their first expectations. However, Aarons and Gittens (1999) insist that all children with autism have aspects of normality and these can be enjoyed. As with all children, autistic children can give both pleasure and pain to their parents.

Doctors can help parents and teachers to plan programmes of education, by telling them the details of the child's handicaps. Communication about the child's condition should be an on-going, two-way process. Parents and teachers, through their interaction, should be supportive of each other, as well as focusing their attention on the specific needs of the autistic child.

3.3.2. Treatment Models

Approaches to the treatment of autistic children can be classified into three categories: psychodynamic, pharmacological and behavioural.

(i) Psychodynamic Model: This is based on the premise that autism is the result of the child's withdrawal from a world perceived as hostile and dangerous, because of the psychological pathology in the parent, particularly the mother (Schreibman, 1988). Its most ardent supporter is Bettelheim (1967). The child is removed from the "hostile" home environment to a residential setting where therapists encourage him/her to reach out for experiences and to develop a strong concept of self and of the world. However, as indicated in Chapter Two, the assumption on which this model is based is now largely discredited. Moreover, investigation has not supported the effectiveness of psychotherapy in the treatment of autism (Bartak and Rutter, 1973).

(ii) Psychopharmacological Treatments: Since no specific neurochemical cause has been identified for autism, no specific drug cure has been possible. Efforts have, however, been made to assess the effects of various drug agents on specific behaviours. Treatments have included stimulants, anti-depressants, psychedelics, neuroleptics, thyroid hormones, amphetamines and megavitamins. However, results are difficult to evaluate because of issues related to medical dosage, and experimental issues (small samples, lack of controls) and lack of objective measurement of appropriate dependent variables.

(iii) Behavioural Treatment: In contrast to the two previous models, the behavioural model does not seek to cure a central process or disease, but to view autism as a syndrome of specific behaviours, to be tackled by manipulating those aspects of the environment that affect them, in line with

established learning theory. For example, Parks (1983) has described how her daughter was taught, using operant conditioning (in this case, clocking up points on a golf counter) to greet people, perform household tasks, reach for new experiences, and control verbal "tics" and other undesirable behaviour.

Lovaas *et al* (1973) have demonstrated the importance of parent-training to reinforce behavioural therapy, (see below for fuller details of Lovaas' on-going research). Another important treatment extension is the child's school.

3.3.3. Extended Treatment Environment in School and Community

I. United States of America

Until the mid-1970s, most educational systems were not very responsive to the needs of autistic children and many were denied access to public school programmes (Schreibman, 1988). This resulted in many autistic children being placed in inappropriate residential institutions. However, Public Law 94-142 of 1975 provided a federal mandate for public education for autistic and other disabled children, and stipulated that it be provided in the "least restrictive" environment possible. This requirement led to extensive research directed at the development of effective procedures for educating autistic children in the classroom, and on the identification and development of "functional" curricula (Johnson and Koegel, 1982). Other research has focused on the classroom environment and teaching methods.

After intensive educational programming, many autistic children have been able to make the transition to an integrated class, or even a mainstream school situation in a class populated entirely with "normal" children. Schreibman (1988) refers to Koegel *et al*'s (1982) comments on the potential problem of segregation as well as Ehlers and Gilberg's (1993) finding that autistic children can learn from observing non-disabled peers as a model of correct responses. Programmes such as Schopler's Treatment and Education of Autistic and related Communication disabled Children (TEACCH) programme provide a combination of services including diagnostic evaluation, special education, consultation, parent training and counselling, and facilitation of parent group activities (Schopler and Olley, 1982).

Before continuing, it is important to detail here an approach which has been evaluated and used with great success over many years and in many different settings. TEACCH manages the individual's environment through structured teaching and an emphasis on task completion. Its principal aim is to adapt the learning environment to the needs of the person with autism, as opposed to vice versa. Thus, Schopler and Olley (1982) claim that TEACCH works with anyone from all parts of the autistic spectrum. This programme covers most aspects of family services connected with autism by both language-focused and behaviour-focused programmes that are drawn up on an individual basis for use in schools and work. Because of these facts it claims to enable participants live purposeful lives as members of their communities.

Jordan and Jones (1999) describe the TEACCH structure as '...a concession to the autistic way of thinking: what is created is an autistic environment where the individual way autism can function' (p. 30). Recognising the problem that the autistic child may never learn to function in the everyday world, Jordan and Jones (1999) note that TEACCH has resolved this dilemma by creating a '*cradle to the grave*' service. From

such a statement obviously there is little expectation by them that an autistic person can ever function normally.

Unfortunately, following the dissemination of Jordan *et al*'s findings, some Local Education Authorities (LEAs) in the UK have begun to rely on it to argue against parents wishes. According to Sallows (2000), because Jordan and Jones' report contained many inaccuracies and unfounded conclusions, this resulted in some children not receiving appropriate provision. This will be discussed further in the next sub section.

Such an approach as TEACCH is endorsed by the National Autistic Society of the UK. Also, a further extension of treatment environments includes the development of programmes for adolescents and adults, including group homes, transition homes and other community-based resources.

II. The United Kingdom

The 1981 Education Act emphasised provision for the individual special needs of each child. This Education Act has been replaced by the 1996 Education Act which replaces the 1993 Education Act which details the Code of Practice for Special Needs Children in the United Kingdom (UK).

The Code of Practice states that children with identifiable problems that may affect their ability to benefit from mainstream education are referred by the local health authority or school and have their needs considered by all relevant professionals, in partnership with the parents. The outcome of the "statement" should result in the successful placement of children in schools which cater for their particular needs,

regardless of diagnostic labels. Local Education Authorities (LEAs) are required by law to meet special educational needs, either by making additional resources (such as support staff) available in a mainstream school, or by providing education in a special school or unit. Autistic children vary considerably in academic capability and behaviour. Depending on the degree and nature of the child's difficulty, his/her needs may be met by a special school for autistic children, a school or unit dealing with language disorders, a school for children with moderate learning difficulties, or (more rarely) in mainstream schools. Progress and needs are reviewed annually (Aarons and Gittens, 1992).

Other help available to parents of autistic children includes Portage Schemes (i.e. positive reinforcement achieved through task centred activities delivered to mainly preschool children by their parents with support from a Portage worker with special training) and respite care. Some parents may qualify for an attendance allowance from the Department of Social Security. The National Autistic Society runs special schools, provides support and information to parents, and has published papers directed at teachers, about access to the National Curriculum for autistic children. In addition to these there is access to a range of both educational and social resources, such as Hanen, TEACCH and the recent Early Bird NAS project. These will be detailed later.

It is considered by many that parents may believe that one-to-one input from an adult is the only way forward. This can be socially isolating for the child, because when an adult is always present as a support, socially normal children tend to interact with the adult and not other children. Therefore, young children with autism need opportunities to mix with their peers and to learn from them in a social setting. Similar to their peers, they need time to mature and gain living skills, and social experiences which may underpin their future learning.

3.4. Impact upon Specific members of the Family and their Management of Stress

3.4.1 Impact on Family

Donenberg and Baker (1993) compared the impact of young children's behaviours on their families using several measures of family functioning, such as socialising within the extended family and outside the extended family. They used a variety of methods such as clinical control groups, which focused on pre-school aged children to ascertain parents' perception of impact and stress. Their main findings were that members of the immediate and extended family reported that on the whole they re-acted to the behaviours of the autistic family member differently within the two situations. Generally, within the close family circle, whilst some felt extremely uncomfortable and embarrassed, it was much preferred as there was support in the form of other family members who understood such embarrassment. However, outside the privacy of the family many reported distancing themselves from the impact of the abnormal behaviours displayed by the family's autistic child.

The degree and perceived variations of response to the impact on the various members of the family circle was not explored. This could be an area for further research to ascertain which factors, if any, influence the positive and negative responses to the various behaviours of the family's autistic member. If these could be identified with further research into *the why, the where, the when and the how,* then appropriate support, family group and individual therapy, and if necessary, training could be implemented to aid individual and group members of the family to cope better with such situations. Aiding family members to recognise why they are reacting or not reacting, at certain

times and during certain situations, to the behaviours of their autistic family member could have a twofold spin-off.

Firstly, this could afford further positive responses to unacceptable behaviour which will not compound or aggravate a potentially explosive situation. And secondly, by identifying individual stress levels and stress stimulators associated with the autistic child's behaviour patterns each family member may be supported and, thus, enabled to control and handle their own mood swings and responses. Group family therapy (cf. Porter and O'Leary, 1980) reveals that marital disharmony or breakdown may have been avoided had family members, especially the parents, been encouraged and supported to openly discuss their true inner feelings. By so doing, parents especially could have been a source of support and encouragement whilst attempting to deal with the discord and disruption in the quality of married life they were experiencing because of their autistic child's behaviours and incessant demands. All parents in this situation reported a sense of continuous exhaustion and no respite from the stresses being experienced. Most parents further reported that at times each blamed the other for the condition of their child. Also, they regretted that they had taken out their frustrations and deep senses of guilt and anger on their marital partners, and at times on their other children and members of their extended families.

3.4.2 Impact on Parents

Konstantareas *et al.* (1992) reported that there is a growing literature on the confusion, embarrassment, anger, helplessness and feelings of depression which may accompany parental reactions to having a dysfunctional child, and an autistic child in particular (cf. Bristol and Schopler (1984); DeMyer (1979); Konstantareas and Homatidis (1988)). Further, Konstantareas *et al.* (1985, 1992) researched the specific child characteristics and their severity of interaction in a complex fashion with parental personality characteristics, and the strategies and coping styles implemented by each of the personality types identified. Predictably they found that the more placid and secure was the personality of the mother, especially, the more both she and the father were able to

contain and reasonably cope with extreme behaviour patterns from their autistic child, each giving the other support and respite when needed.

Some parents reported that the child's disability was only a potential stressor and once they had begun to recognise that it was acceptable for them and their other children to *take time out* without feelings of guilt from the harrowing stress of their autistic child, relationships between the parents and then between the immediate family members improved enormously. This in turn resulted in the parents and then the rest of the family reporting better coping strategies and better senses of positive responses and support for the autistic child.

As Dumas, Wolfe, Fishman and Culligan (1991) report from their American study into '*Parenting Stress, Child Behaviour Problems and Dysphoria in Parents of Children with Autism, Down's Syndrome, Behaviour Disorders and Normal Development*', there are striking similarities between the stresses associated with the upbringing of exceptional or non-disabled children and the stresses associated with the upbringing of autistic children. For example, some of the challenges that parents of exceptional children faced in their child rearing tasks were constant high demanding behaviours; frequent mood swings and attention spans; frequent outbursts of uncontrollable frustration and anger; destroying own toys and work and that of siblings; at times physically attacking parents, siblings or other family members etc. (cf. DeMyer (1979); Griest, Forehand, Wells and McMahon (1980) and Patterson (1980)), all of which resulted in family disruption and/or parental psychopathological illnesses. They also confirmed the results reported by Mash (1984) that there is a direct correlation between the differences in maternal stress which arose from child characteristics and behaviours.

Further, as Konstantaraes, Zajademan, Homatidis and McCade (1992) found individual characteristics of children with handicaps were often related to both marital discord and disruption in the quality of family life and as DeMyer (1979) reported, family conflict is directly associated with the challenging outcomes of dysfunctional behaviours engendered by the need of the carers of dysfunctional children for considerable energy and long-term commitment to therapy.

Dumas (1986); Marcus (1977) and Wahler (1980) identified the stress and related problems associated with the increased social isolation imposed by the socially unacceptable dysfunctional behaviour of autistic family members. Also, Marcus (1977) noted that concern regarding the child's future, in particular in cases of Autism, where self-sufficiency was very unlikely, caused extreme stress in some cases. McCubbin (1998) found that, in addition to the above, lone parenthood was strongly associated with more stress experienced by the single parent. All of these factors were found to contribute to marital disharmony or breakdown of the marriage, which could not sustain the extreme stress being experienced by one or both parents, each or one of whom blamed the other for the medical condition of their child and/or for the stresses related to the rearing of their child. They also felt actively rejected when their spouse devoted all energies to their child to the exclusion of their partner (cf. Porter and O'Leary, 1980).

In addition, high stress risks were identified as being caused by the magnitude and intensity of behaviour problems of autistic children. For example, the burden of care imposed on the parents (cf. DeMeyer (1979); the unpredictability of prognoses (cf. Holroyd and McArthur (1976), Kazdin (1980)), the role required of parents to act as the qualified therapist for children by building speech and language skills: by building and sustaining the acceptable shaping of behaviours, plus, acting as the supervisor as a result

of behavioural excesses, all compounded to heighten the stress being experienced by parents and the extended families of autistic children.

Whilst acknowledging the above, Dean and Jacobson (1982) designed experimentation to explore the relationship of the personality of the parents and the outcomes of learning and/or dysfunctional behaviour in their offspring. They found that parents of exceptional children, especially the mothers, have personality profiles on standardised inventories that are more deviant than those of parents of non-disabled children but very rarely as elevated as those of adults with psychological or psychiatric problems. Similarly, Bristol and Schopler (1984); Bugental and Shennum (1984) and Kazak and Marvin (1984) found that developmental and behavioural difficulties in children were correlated with decreased self-esteem regarding parenting skills and increased negative perceptions of the child (cf. Holleran, Littman, Freund and Schmaling (1982), with increased and elevated anxiety and depression being prevalent (cf. Friedrich and Friedrich, 1981).

Arising from much of the research cited above, Forehand, Furey and McMahon (1984) explored the question of whether stress is handicap specific, although it is unclear what differences are perceived in the amount and the type of stress experienced by parents of exceptional children. This is because parents of exceptional children may experience a general *distress* that reflects the interrelated nature of many of their daily stressors. Moreover, they found that there were greater commonalties than differences in the psychological functioning in parents of exceptional children; therefore, they concluded that a non-categorical approach should be adopted when considering prevention and treatment.

Regarding the impact on fathers, studies by Cummings (1976); McConachie (1989), and Goldberg, Morcovitch, MacGregor and Lojkasek (1986) noted that they were peripherally affected, as the fathers of exceptional children experienced no greater stress than the fathers in the control groups (cf. Kazak and Marvin (1984)). However, Bristol and Schopler (1984) arrived at the opposite conclusion, having researched the same comparisons. Throughout the review of literature associated with studies into the stress impact on families, similar conflicting conclusions are found. For instance, Mash (1984) found that the younger the sibling in a family with an autistic member, the more stressful the impact was. Inasmuch Bristol and Schopler (1984) and Gallagher, Beckman and Cross (1983) explored this area, they concluded that it was with older siblings in a family with an autistic member that more stress was identified. They suggested this may be because older siblings were developing interpersonal relationships with their peer groups and because the onset of adolescence, general self consciousness and low self esteem during adolescence contributed to the heightening of embarrassment and thus stress in admitting that a sibling was autistic and displayed extreme behaviour patterns.

Interestingly, Cummings, Bailey and Rie (1966) found no differences in the impact of having an autistic sibling related to the age of other siblings. Patterson (1980) upheld these conclusions by finding that the gender factor was related to the intensity of the impact; exceptional boys caused more stress for their parents than exceptional girls. Whilst personality traits were not taken into consideration in this study, cultural elements were briefly mentioned. That is, in certain societies males are regarded as being slightly more cherished than females because of their earning capacities. On the other hand, Cummings *et al.* (1966) reported that there was no difference of impact of gender.

Donenberg and Baker (1993) concluded that the impact of the autistic child's characteristics was that parents of children with autism and behaviour disorders

experienced statistically and clinically higher levels of parenting stress than parents in the other two groups. This increased stress may represent the child's characteristics, more than the parents' sense of adequacy. Likewise, mothers of children with autism and behaviour disorders experienced statistically and clinically higher levels of dysphoria than mothers in the other two groups, which appeared to be specifically related to the stresses of parenting exceptional children rather than to personal dysfunction.

No major effect of children's age or gender was found across the four groups, except for the fact that mothers of younger (less than 7 years 5 months) autistic children reported greater dysphoria than mothers in the other three groups. Thus, parents of children with behaviour disorders reported that their children presented behavioural difficulties that were statistically and clinically more intense and numerous than those of all other children. Further, mothers, but not fathers, of children with autism and behaviour disorders identified that they were mildly depressed to extremely depressed with the stresses of having to cope, especially without support (Donenberg and Baker (1993)).

Sharpley, Bitsika, and Efremidis (1997) conducted questionnaire research to determine whether parental stress, anxiety and depression arising from parenting an autistic child could be shown to be related to gender or alleviated by social support. Although they had a high non-return rate, viz 1,076 questionnaires sent and 219 returned, they found that the child management difficulties experienced were mainly behavioural. That is, 35.9% of the cohort found continuous difficulties which led to stressful situations. 81.9% reported sometimes being stretched beyond their limits and abilities to cope. The frequency of such situations was felt by 46.4% to be 1 to 5 times per month, with 11.1% reporting that more than 15 times per month they were stretched beyond their

limits. Thus, the above stressful situations were relatively frequent experiences for more than 1 in 10 of the parents in this study.

Similarly, 41.8% of the respondents reported experiencing moderate levels of anxiety, with 18.6% and 9.1% reporting high and severe anxiety levels. Within this cohort of respondents Sharpley, Bitsika, and Efremidis (1997) found that females reported higher anxiety and depression in comparison with males. This can be accounted for by the fact that in most cases it was the mothers who had primary responsibility for the well-being of the autistic child. All reported frequently being stretched beyond their limits and having to rely upon assistance by family members to cope in order to produce reductions in their anxiety and depression. Interestingly, most of the females in their study reported a greater level of confidence in handling their child's major problems and an increased confidence in handling their child's current major difficulty.

Aarons and Gittens (1999) advocate the importance of respite care, for children who are especially difficult to manage. They suggest schemes provided by both the voluntary sector and local authorities. Such schemes can extend from babysitting services to residential placements for weekends and holiday periods. Examples of these are 'Contact-a-Family' and 'MENCAP' nationwide organisations.

Thus, the identified needs of effective and frequent home help, particularly for those parents who are not well themselves, was highlighted with the need for increased understanding by the family. This, then raises, the question of appropriate parental training.

Horner *et al* (1988) stated that violent behaviours, such as aggression, self-injury, and other destructive acts, can be stigmatising and jeopardise opportunities for social interactions and community participation. Thus, from a family perspective, the challenging behaviours that are demonstrated by a family member with disabilities can represent a significant impediment to the establishment and maintaining of family

routines, social interactions, as well as the quality of family life potential. Because of these difficulties, Bailey *et al* (1986) advocate that it is, therefore, important to obtain information about the kinds of problems that families experience and the kinds of resources that are most needed to deal with some of the stresses and problems being experienced by families when faced with a family member's challenging behaviour.

According to Dunlap, Robbins and Darrow (1994) much of the relevant literature over the past two decades has focused on training parents, and sometimes siblings, to use management strategies based on behaviour modification principals to cope with behaviour problems. Dangel and Polster (1984) advocate manipulating rewards and punishments; their results demonstrated favourable outcomes of improved behaviour patterns. In contrast, Robbins, Dunlap and Plienis (1991) show that some families do very well in the context of behaviour management strategies, whilst other families fail to demonstrate the same level of benefit. Behaviour management now is the use of positive reinforcers to encourage and strengthen desirable adaptive behaviour (Randall and Parker, 1999). For example, if the autistic family member enjoys throwing a ball, then this could be given as a reward when appropriate socially accepted behaviour is demonstrated. After a review of these findings LeLaurin (1992) concludes that there is a definite need for individualised programmes of family assistance.

Although many professionals now accept that family support must be tailored to the individual strengths, needs and circumstances of the family situation (Dunlap and Robbins 1991; Turnbull, Turnbull, Summers, Brotherson and Benson 1986), there has been little research to identify the kinds of services and supports which are needed to support families who have members with challenging behaviour problems. Thus, there is little data to indicate the extent to which such resources are perceived by parents to be of benefit, despite the fact that families are the primary caregivers. Because of this lack of essential data Dunlap, Robbins and Darrow (1994) carried out a questionnaire survey of the resources parents thought would be helpful in managing the challenging behaviours

of their family member. The parents' responses indicated a high frequency of aggressive and other destructive behaviours occurring more than once or twice per day. Teachers, family members, and published materials were identified as the most helpful of currently available resources. Also, the respondents described their family members with autism as exhibiting a large number of challenging behaviours which were perceived as embarrassing and stressful. Psychologists were not identified by very many respondents, but those who did mention psychologists in Dunlap *et al*'s study, found their support to be very helpful.

Dunlap *et al* (1994) conclude that their data offer a step forward towards helping professionals to appreciate the kinds of stress and the wide range of needs that are experienced by families with autistic members.

3.4.3 Training

As stated by Sharpley, Bitsika, and Efremidis (1997, page 25)

> 'If parental confidence in their ability to handle their child's major problems is directly influenced by their confidence in another family member's understanding of their child's problem, then this raises an important issue for training parents and care-givers in how to deal effectively with children with autism. Clearly, while it is vital to train parents in behaviour management of their child with autism, it appears to be similarly important to train those immediate family members in the same skills, thus contributing to the parents' well being and their confidence, self-efficacy, and future ability to deal effectively with the demands of parenting a child with autism'.

Therefore, Sharpley, Bitsika, and Efremidis (1997) suggest inclusion of family *social support* providers in training workshops, conferences/meetings with counsellors and/or

support workers. Based on the results detailed above, future research would be useful on the relative effectiveness of assistance provided by family members versus governmental agencies. Also, an intervention based study is needed, incorporating the comparison of family members (as well as parents), who received training with those who had no such training.

Koegel, Bimbela and Schreibman (1996) studied the effects of two different parent training programmes with the families of 17 autistic children. The programmes were Individual Target Behaviours (ITB) and Pivotal Responses (PRT). The full spectrum of socio-economic status was represented in the families, who were randomly assigned to either of the training conditions. The aim of their study was to assess whether different parent training interventions might differentially influence parents' global style of interactions with their children. The PRT intervention emphasised the principles of motivation and responsivity to multiple cues, whereas, the ITB intervention was in a format of teaching one target at a time.

They concluded that the type of parent training may have a positive influence on reducing stress in everyday life for the following possible reasons. The more naturalistic PRT treatment approach generalised to the setting of the study (lunchtime home setting) and the parents demonstrated less difficulty with incorporating the treatment procedures into their daily mealtime activities. Also, the interactions associated with this treatment approach were more pleasant than no treatment at all or of the ITB treatment. Koegel, Bimbela and Schreibman (1996) concluded that different types of parent training interventions can differentially influence the level of stress that exists during general family interactions outside of the specific treatment activities. These results support the conclusions of Polster, Dangel and Rasp (1986-87); and Schaefer and Briesmeister (1989), that parent training is an effective form of treatment delivery. Moreover, as reported by Baker (1988), it is sustainable.

3.5 Applied Behaviour Analysis

Before reviewing the literature related to the above, within the context of this study Applied Behaviour Analysis is the application of knowledge from Behaviour Analysis that aims to enhance the life of individuals. Behaviour analysis is the study of antecedents which are associated with the production of specificied behaviours and the consequent reinforcement or extinction of these behaviours (e.g. Murphy and Wilson, 1985). The following is relevant to the results of the field data collection of this research because, in general, successful parenting skills are handed down from one generation to another within the culture of Kuwait. In real terms this means that essential child rearing skills are learned in this way rather than through any formal instruction. Such skills are successful in most everyday situations, but, parents of autistic children do not enjoy this experience, because past experience of rearing autistic children is not available.

Keenan and Dillenburger (2000) cite that on 17 March 1997 an article appeared in *The Belfast Telegraph* that outlined the successes that had been achieved by an Asperger's Syndrome child. This resulted in much public interest into the behavioural methods used for teaching children with autism. Thus, in June 1997 Professor Newman from the Association in Manhattan for Autistic Children conducted workshops on Behaviour Analysis for parents and professionals interested in autism. After these events a group was formed, called Parents' Education as Autism Therapists (PEAT).

3.6 Alternative Treatments

From the outset there is much scepticism about the effectiveness of many alternative treatments, therapies and claimed cures. This is based upon the fact that many researchers cannot see a panacea for such a variable condition as autism, because there are so many different possible causes. Examples of such alternative treatments, therapies and cures are given below:

3.6.1 Drug and vitamin therapy

Aarons and Gittens (1999) state that none of these medication programmes have proved to be successful despite some early optimism. Equally, allergies to certain foods, and

food additives, such as tartrazine have been linked to hyperactivity in children. Thus, many practitioners advise parents to consider monitoring the food intake and effect on their children with autism, as restriction of chocolate, certain fizzy drinks, milk and milk products has resulted in an improvement in the behaviour of some children. However, it is emphasised that these are not cures for autism. Parents have noted that episodes of particular behaviour would seem to be linked to certain foods as well as to possible environmental factors.

3.6.2 Higashi

Dr. Kiyo Kitahara's original Higashi School was established in Tokyo in 1954, where daily life therapy was practised. This therapy emphasises group activities under the guidance of trained teachers, who use intensive physical activities under a highly regimented schedule, preventing children with autism from lapsing into their autistic patterns of behaviour. Whilst this method is generally approved of in terms of a structured programme which demonstrates very positive effects, it does not address the social and communication impairments which are intrinsic to the condition of autism. Because of its claimed successes, Higashi has attracted much media attention. Some parents in the UK have sent their child to The Higashi School, Boston, USA, where an integral part of the school curriculum is based on vigorous exercises advocated by Dr. Kiitahara. A similar type of school is due to be opened in the UK.

In their review, Jordan and Jones (1999, p. 101) state that there were then 26 children from the UK attending the Higashi School in Boston, USA. Their first paper describes the evaluation of a four months study of the effectiveness of treatment offered. It reports that the sample demonstrated a significant increase in daily living skills. Their second review paper relies upon retrospective reporting from parents and teachers, and states that the largest gains were in daily living skills and a reduction of aggression. Both results indicating an increase in achievement through exposure to the Higashi programme.

3.6.3 Option Method

This is a USA based approach where parents and children spend two weeks at a centre in Massachusetts, receiving intensive therapy. During this intensive two week therapy, parents are taught the rationale and philosophy behind the Option Method, whereby they are guided by a trained mentor to accept and enjoy their child regardless of their autism. The principal philosophy is for parents to have a 24-hour commitment to their child. This involves the support and help of a team of volunteers and friends, as well as adapting a room at home for the sole purpose of the Option Method. The Option Method encourages parents to take their child's lead by allowing initiating of activities, thereby empowering the autistic child to 'choose not to be autistic'.

Whilst it would seem that such a scheme does not make logical sense as many of the activities of autistic children are inappropriate, some parents have reported significant successes in the changes of behaviour achieved through helpful guidance about how to develop play with their children. Williams (1996) states that proponents of this approach make extravagant claims which may be misleading parents. In fact, such claims can be harmful as they can seriously compromise the well-being of the child. Further, such claims seem to be contradictory and in direct conflict with the claimed principal philosophy that 'parents are to accept and enjoy the child for who he/she is'.

3.6.4 Behaviour modification – Lovaas

During the 1960s, Lovaas developed behaviour modification methods in the USA, but because of the form of punishment used to reduce inappropriate or self-injurious behaviour it was stopped. This form of behaviour modification was viewed as extreme

and, therefore, unacceptable as aversion therapy involves the use of unpleasant stimulus to reduce undesirable behaviour. Because of this it was deemed as unethical, and as there is little evidence to support any improvement over a long period of time, such therapy was suspended.

However, modern reward based behaviour modification methods have become extremely popular as an intervention for young pre-school children with autism, and Lovass (1981) developed a newer method which is continuously monitored and re-evaluated.

> "...the Lovaas method has been successful in demonstrating that early intensive intervention in autism can be very effective for a substantial proportion of children'
>
> (Jordan *et al* 1998, Research Brief).

Very briefly, the Lovaas method (1981) involves working with children following a curriculum similar to that advocated by Maurice *et al* (1996). The curriculum starts with very fundamental skills such as sitting and responding to simple one or two word commands, such as *come here*. Once basic attending skills are established a foundation is built to develop advanced skills, such as speech or abstract conversation. The results to date show improvements in behaviour which may be effective because of focusing the child's attention.

However, Tager-Flusberg (1996), Wing (1996) and Aarons and Gittens (1999) identify that transfer of skills to other situations in this behaviour modification methods

are problematic. Also, they found that some parents become so focused on this one-to-one structured programme, that they fail to realise their children would benefit from wider and less structured social activities. Thus, Lovaas' ethos of behaviour modification does not fit with current research findings related to the nature of autism, because it marginalizes the cognitive nature of the condition.

Barry and Samahria Kaufman (1997) developed the *Options* approach based on the personal experiences with their son Raun, who is severely affected by autism. Having been told that there was nothing that could be done to help the child, the Kaufman family enacted a programme centred on the philosophy totally and freely accepting the child. This involves parents being encouraged to join in with the activities of the autistic child's choice (often self stimulatory behaviour) (cf. Kaufman 1997, Howlin 1997, Jordan *et al* 1998).

However, Howlin (1997b, p. 58) concluded that 'there are no controlled investigations of this form of treatment and apart from the Kaufman's own writings, no reports of the long term effects of intervention'. However, Kaufman (1997) argues that this is due to the Option Institute wishing to spend its time helping families rather than generating research. Whilst, this is a distinct disadvantage regarding demonstrating well founded bases and good practice, the researcher would recommend implementation in Kuwait based on the evaluation points of Options detailed in Chapter Nine.

Another programme for use with autistic family members is the Treatment and Education of autistic and related Communications Disabled Children (TEACCH) which is based largely on the experiences of the state of North Carolina, USA through the work of Dr. Eric Schopler. Schopler developed the method of structured teaching using a visual approach to work with autistic children. However, Mesibov (1997, p. 26) states that unstructured teaching gives the child the opportunity to decide these things, whereas, structured teaching is defined as having the adult (teacher or parent) determine how the child will learn as well as the materials and length of the session.

The usage of TEACCH in the USA provides services for individual autistic patients throughout their lifetime, as the focus is on giving young children the skills needed for adulthood. Thus, as Jordan *et al* (1997) describe TEACCH as functional and vocation skills being taught from a young age, and because there is a strong emphasis on communication training using pictures, symbols or icons if the autistic children have a limited verbal ability, this could be utilised into national programmes in Kuwait. Further, both teachers and parents are enabled to use this method after a comparatively very short period of induction: three to five days of training.

Jordan and Jones (1999, p. 79) note that the goal of the TEACCH programme is not to treat the autism directly, but rather to provide a *prosthetic environment*, so that the autistic family member's difficulties (which are believed to be part of the autism, hence cannot be changed, and must be accepted therefore) will cause minimal stress and anxiety to parents and other family members. As stated above a major goal of the TEACCH

method is to teach functional and vocational skills, '..to enable (family members) to function semi-independently as long as there is a structure' (Jordan and Jones, 1999, p. 80). Thus, family members in TEACCH programmes spend most of their day working independently in prevocational activities involving matching and sorting. It is argues because of this that one of the strengths of the TEACCH programme is that previously noncompliant difficult to manage autistic family members learn to follow visual, often pictorial, instructions, to help them complete their assigned tasks with very little supervision.

However, Jordan and Jones (1999) state when reviewing the research on TEACCH that '...there has been surprisingly little done to evaluate the program in terms of outcomes..' (p. 88). This is based on the assumption that although Mesibov's (1997) review of TEACCH evaluation studies, are largely based on parental reports of satisfaction '... does not constitute scientific evidence' (ibid. p.88). TEACCH has borrowed several concepts from behavioural approaches (cf. Watson, Lord, Schaffer and Schopler, 1989, p. 9), including the idea of mastery of taught skills. For example, Watson et al (1989, p.89) states that '..the assessment of student progress helps the teacher to make decisions about when to move onto a new objective, and when to simplify an objective....the criterion might be appropriate behaviour on 80% of trials for two consecutive days.' Thus, initially it is necessary for items to be repeated, allowing the child to use memory for routines as a learning aide. This is seem by Sallows (2000, p. 31) as '...being a strength of autistic children..'. He goes on to point out that whilst Jordan et al (1998, 1999) describe Lovaas' method as doing this, Lovaas states that children should

enjoy treatment and that novelty and a wide variety of positives should be used to maintain motivation.

Aversives were generally accepted during the 1960s and 1970s, and Lovaas advocated the use of them at that time. In their TEACCH training manual, Schopler *et al* (1980, p. 121) describes the use of '..aversive and painful procedures (such as meal deprivation)..slaps or spanks on the child's bottom (p. 121), or ..electric shock, unpleasant tasting or smelling substance (p.122) as appropriate interventions if positive methods are ineffective (p. 48). However, Lovaas has dropped their use in his revised programmes, because at this time he was seeing most of the children in an inpatient setting and there seemed to be no other way to provide treatment.

He changed his views as he observed the impact that this policy was having on already stressed parents. So to reduce the stress placed on them whilst still providing the necessary manpower, Lovaas developed a pool of volunteers. Because of his concern for parents he advised them to get some *help to prevent burn-out.* Lovaas *et al* (1981, p. 4) suggests to parents to '...hire assistants and form a teaching team...composed of between four and eight people, each working about four to eight hours per week'. His reason for encouraging parents to do some direct work was in order that they would be familiar with the treatment procedures, and with their child's progress. This then would allow parents to help their child use their gains in everyday life.

Further, Lovaas (1989) discourages treatments during the first six months that may result in psychological stress or irritability such as Auditory Integration Training (Rimland and Edelson, 1995), for which there is no supportive research (cf. Zollweg, Palm and Vance, 1997), and FastForWord (Tallal *et al*, 1996), which is inappropriate and frustrating for children with a language age below five years (Deditz and Layendecker, 1998). The child's response to behavioural treatment must be monitored very closely to optimise progress whilst minimising frustration. So Sallows (2000) concluded that Lovaas had nothing against treatments supported by research, which complement rather than detract from behaviour therapy. In fact, in recent years, Lovaas' group has stated that many procedures developed by other research have potentially been beneficial. For example, these include visual (pictorial) and written cues (Krantz and McClannahan, 1993), as well as visual schedules and instructional sequences (McClannahan and Krantz, 1994), and visual strategies for addressing social skills (Gray, 1994; Charlop and Milstein, 1989).

Although caution, and regard for the results of the above cited reviews, must be taken, such a method of intervention as the programme TEACCH could be introduced into a national programme within Kuwait. This could initially be as a research based intervention programme. Moreover, care must be taken if TEACCH is to be implemented into Kuwait, as Lovaas (1987) does not advocate Schopler's treatment should be delivered via a classroom model because the required one-to-one contact cannot be provided, which has been used by Jordon *et al* (1999) who found that the *Lovaas classroom* was less effective at building imitation than parents were at home. Sallows

(2000) cites this as clear evidence that a classroom setting was not delivering Schopler's behavioural therapy as prescribed and therefore, must invalid some of Jordan and Jones' (1999) conclusions, although they are very supportive of the behavioural interventions. Further, in the UK the National Autism Society (1997, p. 98) note that '...behavioural approaches remain a part of the curriculum (in UK school programmes for autistic spectrum disorder), and often underpin the structure that is seen as essential...'.

Thus, provided the TEACCH method is introduced in Kuwait as a one-to-one contact as described above, this could provide an essential element of double support, i.e. concentrated efforts in school followed by appropriate support from the family. The results of such an endeavour could contribute towards the existing provision for autism in Kuwait as well as the current international research data and reviews, but involving a predominantly purely Islam community. This would also provide opportunities for Kuwaiti families to experience western world methods, which would allow them to make decisions about which is their preferred methods to be used to support their family member. It should be noted that the TEACCH manual used by parents for their in-home programmes (Schopler, Lansing and Waters, 1983) includes many of Lovaas' early programmes, such as non-verbal imitation, which were reported as being beneficial.

Lovaas (1989) has also been working for several years on developing a reading and writing programmes for children who are unable to use speech fluently (Waltham-Lovaas and Eikeseth, 1998). Voice output devices as well as signing have also been found to be beneficial for some children (e.g. Bondy and Frost, 1994). Thus, when Jordan

et al (1998) state that Lovaas' approach is individual and adult oriented rather than group and child orientated, Sallows (2000) says this is untrue. Children are taught on a one-to-one basis initially because it has been found that this is the best way to build skills in a child who does not attend to peers, or does not learn from imitation, and/or does not understand or use speech (Dawson and Osterling, 1997).

Lord and Schopler (1989) state that a structured training session, where there is no pretence that the events are naturally occurring, and in which the student is given a concentrated period of practice in making the same type of response to the same type of stimuli, '..is often the best way to start teaching a new skill' (Watson et al, 1989, p. 83). Also, Koegel, Rincover and Egel (1982) recommend that teachers working with autistic children in group environments should structure as much one to one time as possible. This is supported by the findings and recommendations of the California Department of Education (1997), who state that collaboration between parents and professionals must arrive at a set of best practices for effective programmes for individuals with an autistic spectrum disorder. They note that 'grouping children with disabilities with each other may not be in the interest of any individual child, especially if a child's disability includes difficulty in communication or social interaction. As the child tries to communicate, he needs someone who can communicate back' (ibid. p. 66). This report goes on to state that '...there is little or no evidence to show that children with autism learn in group situations' (ibid. p. 74). Moreover, citing Koegel *et al* (1982), the report states that '...research findings indicate that children with autism learn only in one-to-one situations for approximately the first six months of treatment' (p. 74).

Despite all these research findings, whilst group instruction may not be as effective with autistic children at the early stages of treatment as one would wish, many parents feel that sending their child to school will at least provide some benefit for their lagging social skills. Burnstein (1986) found that children at the earliest levels of treatment tended to engage in solitary play if they engaged in play at all. Thus, Sasso, Simpson and Novak (1985) concluded that children placed in a group setting before they had some *survival skills* may learn to follow classroom routines and accept social intrusion by peers, but they did not learn to interact or speak well. Michelson and Mannarino (1986, p. 398) noted that '...research has indicated that socially deficient children do not automatically acquire the necessary social skills through contact with regular students.

It has also been shown that behaviourally disordered children are often ignored by their peers rather than becoming involved in actions that facilitate the development of more appropriate social behaviours.' Therefore, Sallows (2000, p. 33) concludes that '...autistic children get much more out of being with age mates once they have learned to attend to people, to learn by imitation, and can understand and use some speech. The Lovaas program is structured to accomplish this. Peer interaction skills are heavily targeted once the child has these basic skills'.

Interestingly, however, when given the choice between their child learning to communicate via visual, context specific methods versus learning to speak, Eikeseth, Jahr

and Eldevik (1999) found that most parents choose speech. They also found that children who received TEACCH interventions gained 22 months in language skills after one year in treatment against two months for children in a programme which focussed on non-verbal communication. Gresham and MacMillan (1998) found that there is no evidence that the length of time or even the intensity of time spent in school results in increases in the IQs of autistic children. This finding is confirmed by Guralnick (1997) and Lord and Schopler (1989).

Whereas, Perry, Cohen and DeCarlo (1995) described two siblings who had been diagnosed as autistic as having *recovered* following approximately two years of behavioural intervention patterned along the lines of TEACCH. Further, Greenspan and Wieder (1998), perhaps one of the best know advocates of play as a therapeutic method, state that three to five hours per day is required to achieve optimal benefits, and that speech will be enhanced through these interactions. Eikeseth et al (1999) recently found that in a study of two groups of children which both received 30 hours of intervention on a one-to-one basis, showed an average increase in IQ of 18 points after one year compared with 6 points for the *eclectic* group. Language, therefore, increased by 26 months in the TEACCH group compared to 2 months in the *electic* group.

In future studies, Jordan and Jones (1999) call upon researchers looking at comparative effectiveness of different approaches to control for several variables, such as treatment intensity, parental involvement, and what they call the *halo* effect. The halo effect refers to the tendency of parents, who feel better about having an autistic family

member because they are engaged in an effort to help their child, to conclude that the treatment is the cause of their improved mental state and must therefore be effective. As a result, parents report positive changes in their child which are in fact the result of normal daily fluctuations in behaviour. This is why Sallows (2000, p. 38) concludes that parental reporting is a poor measure of programme effectiveness.

Watson *et al* (1989, p. 9) state that '...the influence of behavioural approaches is seen in an emphasis on structure, particularly in the initial stages of teaching new behaviours, on targeting specific behaviours and defining conditions and consequences of eliciting the behaviour, and on the shaping of behaviours through the use of cueing and prompting'. Sallows (2000) suggests that one might get the impression that TEACCH has become quite behavioural. However, when the underlying beliefs and actual practices of the TEACCH programme are compared to those in ABA programmes the reasons for the poor outcome in children becomes more clear.

For example, TEACCH is much less intensive than Lovaas' method by advocating much less one-to-one work compared to Lovaas' five to six hours per day. Further, Sallows (2000, p. 39) advocates that once the child has been taught to imitate gestures (which both programmes teach early in their curricula), TEACCH focuses on functional skills, such as nonverbal communication, self-help and prevocational skills. Whereas, Lovaas focuses on building language and social interaction. These differences are even more clear as ABA researchers believe that all skills can be taught, hence normalcy is theoretically possible with autistic children. However, within TEACCH,

there is a belief based on their own experience that normalcy is not possible. Schopler (1989) states '..with the exception of a very few high functioning individuals, our students difficulties in language comprehension will be a lifelong handicap' (Watson *et al*, 1989, p. 6).

Consequently, Sallows (2000) concludes that this difference in what is believed to be possible leads to very different approaches to goal setting. As stated above ABA researchers look to typically develop the child by identifying areas in which autistic children show deficits, and attempt to design interventions that will result in the child becoming *normal*. Whereas, TEACCH views autistic children as similar to children with mental retardation, and therefore sets goals to build *functional* skills. Watson *et al*, (1989, p. 19) argues that there is no goal to develop speech...only that the child be able to communicate in some way: '...the focus in this curriculum is on expanding the flexibility with which students are able to communicate...and not on teaching students to use a more complex form..'.

Responding to this Sallows (2000, p. 41) states that '...although there is evidence that signing or other visual strategies may help children acquire and use labels (e.g. Bondy and Forst, 1994), I am unaware of evidence that signing results in better articulation, and in fact there was no mention of whether the child's articulation improved'. Furthermore, writers such as the California Department of Education (1997, p. 63) and Hurley-Geffner (1995), have observed a growing uneasiness among parents, professionals and researchers, who question whether emphasising *functional life skills*

instead of skills needed for the development of relationships, such as speech and social interaction, has resulted in a lower overall quality of life for children with disabilities, as well as their families.

Based on an extensive review of the literature and input from many professionals representing several state agencies (special education, developmental disabilities, protection and advocacy, Special Education Local Plan Area Directors, the Autism Society of California, and autism specialists from colleges and universities), the California Department of Education (1997, p. 67) concluded that '...research has shown that intervention and educational programming based on the principles and practices of applied behaviour analysis can produce rapid, complex and durable improvements in cognitive, social-communication, play, and self-help skills. Application of behaviour-analytic principles are very effective in replacing and/or reducing maladaptive behaviour'.

So, in 1999 the New York State Department of Health issued guidelines for the treatment of young children with an ASD, stating that early and intensive behavioural intervention is at present the only appropriate treatment. The guidelines emphasise that there was little value in other currently popular approaches, which did not advocate early intervention, intensive one-to-one instruction and use of systematic behavioural techniques to address behaviour problems and to teach language skills.

Equally of importance, the Picture Exchange Communications System (PECS) was developed by Bondy and Frost (1994) as a means of helping special needs children communicate. It teaches the child to give a small icon/picture or even word to the person that they wish to communicate with. Initially, the child is taught by having a desired object or piece of food close by, but out of reach. The child is then taught to give a picture of the desired item to the communicative partner to request that item, without the adult prompting the exchange (i.e. asking 'what do you want?') (Jordan *et al* 1998). The partner then gets the item for the child.

This method was developed at the Delaware Autistic Program (USA) after frustrations with the limitations of teaching alternative communication methods to these children. However, Bondy and Frost (1994) found that both sign language and picture pointing methods presented difficulties with children who had limited fine motor abilities, or missed opportunities when adult's attention was not gained before the child initiated the communication attempt.

Another concern for Bondy and Frost (1994), was the frequent lack of any initiation of communication by the child. PECS was designed to allow the child to take the symbol of the desired item to an adult and therefore request the item. 'One important positive side effect of this system has been the large number of children who have developed speech following a year or two of starting on PECS program' (Bondy and Frost, p. 30).

Although the PECS programme has not been evaluated in comparison to other programmes, according to Jordan *et al* (1998) it appears to yield gains in the child's ability to communicate, even among those with severe limitations. PECS does appear to be a less stressful approach that teaches the child a *help* response in a one-to-one session using prompting before expecting the response in different more realistic situations.

Jordan and Jones (1999, p. 106) state that

> No approach has yet been entirely successful in producing a methodologically sound evaluation....
>
> (and that)
>
> ...there is really no strong evidence to suggest that one approach for a child with ASD is better than another...(p. 108)

California Department of Education (1997); Dawson and Osterling (1997) and the New York State Department of Health (1999) argue that behavioural structure, family involvement, intensity of intervention, specific generalisation strategies, peer integration and school survival skills are important components and necessary components of any successful programme.

Sallows (2000) concludes by saying that the goal is to continue to develop ways of working with autistic children to enhance their ability to benefit from the type of learning used by typically developing children. They learn rapidly by observation, instruction, and their own problem solving abilities, allowing them to excel intellectually and interact comfortably in social settings. Everyone associated with and involved in the

development of the potential of each individual autistic child must want the same: the best possible therapies and learning outcomes.

So as at this time, no programme will ever meet the needs of every individual, the researcher believes that it is better to have a range of programmes which could cover most of the specific needs of Kuwaiti autistic citizens. This would allow Kuwaiti parents and professionals to make their own decisions as to which programmes are most effective and with research undertaken by the University of Kuwait, this could contribute to international understanding of the causes and the management of Autism.

3.6.5 Sensory integration therapy

Ayres (1986) developed this approach for use primarily by occupational therapists. It is based on the belief that the developing brain is not able to attach meaning to sensations or organise perceptions and concepts in autistic people. The treatment, 'motor planning', involves of activities to stimulate the balance centres, skin receptors and tendon, joint and muscle receptors, because many children with autism display motor co-ordination problems. Some researchers argue that although children with autism have received this type of therapy, there does not appear to be any relevance to social impairments that are the core disabilities within the condition of autism.

Thus, organisational skills are seen as an aspect of impaired central coherence and executive function, whereas, proponents of sensory integration therapy see the

accompanying social impairments as secondary, and call the condition 'dyspraxia' (Aarons and Gittens, 1999, p. 97).

3.6.6 Auditory integration therapy

This type of therapy originated in France and involves the use of a machine referred to as a 'kinetron'. Its principal aim is to re-train the child with autism's hearing through using processed music. Many exaggerated claims are made for this treatment, with a claim of '80% success rate'. But, there is no research to support the theory behind this type of therapy. All that can be said at the present time is that children with extreme auditory sensitivity may be helped, but because there is no contact between the providers of this therapy and the professionals working with the children on a day-to-day basis, conflict of therapies may creep in (Wolff, 1995; Aarons and Gittens, 1998; Gagnon *et al*, 1997).

3.6.7 Family therapy/psychotherapy

Because some higher-functioning children with autism go undetected as actually having autism, they and their families are referred for family therapy. This is primarily because the behaviours displayed are seen in terms of emotional disturbance and/or poor parenting skills. Or, alternatively, sometimes family therapy is offered because some professionals believe that autism has an underlying emotional cause.

Wolff (1998), based on research on the personality characteristics of parents of autistic children, suggested that once the condition of autism has been established an entire family discussion can be beneficial as it is a very helpful constructive approach.

However, he raised concerns related to some parent's anxieties being reinforced by the suggestion that their child's condition has resulted from their mismanagement. Thus, psychotherapy may not be an appropriate treatment for autism, and the claims made for its efficacy. Aarons and Gittens (1999) have found that intelligent, verbal adults with autism have expressed strong feelings of disapproval about the relevance of psychotherapy to their condition and inherent problems.

In the UK *immediate response initiatives* are available to support parents from the moment their child's diagnosis is confirmed, and excellent *outreach teams* with specialisms in autism provide a similar service. Unfortunately, these pockets of excellence of support are outnumbered by areas where parents receive no support at all. There is a need for consistency of approach as well as consistency of quality of support for parents, families and children with autism.

> Autism is a variable and complex developmental disorder which frequently goes unrecognised, or is misunderstood by both parents and professionals. Autism is a complex challenge and a potentially devastating disability. Parents and professional confronting the puzzle need help in putting the pieces together.
>
> (Paul Cann, Chief Executive, The National Autistic Society, 1999).

3.7 Support from within the extended family

Many studies have shown that the extended families of parents with learning disabled children are, in general, very supportive (e.g. Burke and Cigno, 2000). Burke and Cigno (2000, p.45) state that no matter what the family patterns are and how it may change over

time, it still remains the central cog in the care of dependent members (See Beck and Beck – Gernsheim, 1995; Domine, 1997 and Smart and Neale, 1999 for in depth discussions about particular familial types, such as "extended" and "nuclear")

As a consequence of those changes in family composition into smaller and more mobile units, help and support from the traditional extended family are not readily available.

As many grandparents and other family members live some distance apart, Burke and Cigno (2000, p46) state 'The expectation of having at hand every involved, extended family is no longer part of everyday life in the post-industrial period'. This results in low levels of contact and so such support is not readily available and therefore cannot be counted upon.

As families tend to be smaller, this also contributes to isolation and less support. Cooke and Lawton (1984) report that from their research, families such as these will turn to friends and neighbours. Usually this is mainly at times of crisis, Nearly one third of their sample indicated that they did not have access to traditional family support. Burke and Cigno (1995) found that spouses nominated each other as the major source of informal help, followed by grandparents. Teachers were the greatest source of formal support. Manthorpe (1994) found that 98% of disabled children lived with their families and most caring activities were carried out by parents and siblings.

Most research into support from within the family (e.g. Ayer and Alaszewski, 1984, Glendinning, 1986, McIntosh, 1992) cite the mothers' views. Hornby (1992) demonstrated, however, that fathers of disabled children feel isolated, rejected and not supported. Smart and Neale (1999) research social class differences in parenting among fathers who, in general, see their role within the family as the provider, the traditional bread winner. Roberts (1988); Evadron, (1990) and Cigno with Burke, (1997), report that

in the case of a single parent family, the lone carer is the mother, who is unable to work because of her caring responsibilities. Consequently, their samples reported a significant degree of feelings of isolation and other hardships. It is important to note that all these studies concentrate on the parent rather than other support givers.

Thus, the parents of children with learning disabilities are, for the most part, able to gain sympathy, understanding and practical help from their own parents and other family members. The parents of children with autism are, however, less likely to find such unequivocal support. Randall and Parker (1999) report from their survey that although the attitude of extended family members was very important to these parents, many found that support was often marred by negative evaluations.

Many extended family members were not slow in stating opinions which could be interpreted as criticisms. Thus, some parents were told to be more patient with their child and to give him or her more love and attention. Some fathers were particularly aware of criticism and reported various negative attributes in the statements of some family members, believing that they were suggesting that the child had been spoilt and neglected (Randall and Parker, 1999, p.23).

These findings are not new. Luvag (1989) found similar trends in her smaller survey of children with autism in the Philippines and, more recently, Glasberg and Harris (1997) found, in a survey of parents and grandparents of children with autism aged 36 months to 78 months, that the fathers and paternal grandparents differed frequently on issues concerning severity and prognosis. Such discrepancies concerning experiences of family support between parents of learning disabled children and those with children with autism, are hardly surprising given that autistic disorders are more complex and variable.

This writer believes that such complexities may not be well understood by extended family members.

The majority of studies of extended family support have been carried out in western countries and religious and cultural influences are not well researched. Although no comparative studies have been carried out in Arab countries, this researcher has reason to believe that extended family support is more likely to be greater for the parents of children with autism in Kuwait. His premise for this assumption is based upon Islamic teachings which have a very strong influence within the Kuwaiti culture. For example, within the Holy Koran sorah't al noor, A'ayah" 18-34 (English translation is Chapter 18, paragraph 18-34) requires that all Islamic followers' behaviour must be mindful with regard to the family nucleus. This is because the family and its composition are seen as sacred, and as such must always be protected and loyally supported.

Consequently, within the Kuwaiti culture each member of the immediate and extended family will automatically offer support to any other member of the family. Also, it is traditional within the Kuwaiti culture, as indeed the Islamic culture, for members of the family to meet together on Fridays (the Islamic Holy Day) to share a meal. Generally, this is in the home of the eldest family member, i.e. the grandparents. This weekly getting together of approximately 25-35 relations helps to maintain close family contacts and bind the family together. Because of this traditional cultural basis the researcher believes that families in Kuwait are less isolated and less likely to be scattered far afield. This, as stated, results in close family contacts and communities of immediate and extended family members being in weekly, if not daily, contact with each other. As a result of this close family community, appropriate support of time, money, provisions etc. is immediately available.

3.8 Summary of the Chapter

Autism is a combination of specific behavioural characteristics that constitute a special pattern. The key elements are impairments in social relationships, social communication, and social understanding and imagination. Self-stimulation, SIB, inappropriate affect and impaired intellectual functioning are also represented in other populations, whereas the profound deficits in social attachment and behaviour, the demand for sameness, certain speech characteristics and the highly uneven profile in a range of functioning areas may weigh more heavily in diagnosis.

Various treatment models have been tried, depending on assumptions as to aetiology. Of these, the behavioural model appears to be most successful. Education and management involves the combined and co-ordinated efforts of clinicians, parents, teachers and therapists. In the USA and UK, the parents' empowerment movement (represented by the relevant National Societies) together with legislation, ensure that a range of provision is available to meet the special educational needs of autistic children. Various sources of community support and information exist, and extensive research is concluded.

Having given a brief historical outline of the research development of autism, a review and discussion of the relevant literature on behaviour and education and management of autistic children, a review of the provision for autistic children in Kuwait will be given in the next chapter.

Chapter Four
PROVISION FOR AUTISTIC CHILDREN IN KUWAIT

4.1. Introduction

Kuwait is a rather prosperous country with a comprehensive system of social services. The average life expectancy of Kuwaiti citizens[1] is 73.9 years, which is nearly equal to that of the western world (75.9 years) (Kaleidoscope: Current World Data, 1994). Thus, prosperity and supporting social services may be related to this high level of life expectancy.

The responses of Kuwaiti special educators to Western World approaches to the care and treatment of individuals with special educational needs are embedded in Islamic cultural and religious experiences and expectations. Thus, an understanding of the socio-political situation in Kuwait will provide insights into the development of provision for special education needs and autism in particular.

It is only recently that autism has been recognised in Kuwait as a distinct disorder. International statistics indicate that 3-5 cases out of 10,000 new-born children may have some degree of autism. Based on the current population statistics this would imply that there may be some 500-700 cases in Kuwait, though this is only an estimate, as no official figures in regard to autism are as yet available. However, the exact extent of provision is difficult to determine, as there is only one institution catering exclusively for

[1] A Kuwaiti citizen is a person born in the country of Kuwait or if born outside of the country whose parents, especially the father is by definition a Kuwaiti. A Kuwaiti citizen has the right to vote at 21 years of age; receive all legal and constitutional rights; has rights to free health, education, and freedom of religious belief; freedom of speech. The Kuwaiti Government will advance monies for the purchase of a house without any interest on the initial loan. Most citizens repay this government loan at £70 per month. Finally, a Kuwaiti citizen is able to borrow monies from the Government Bank with no interest on the loan.

autistic children, and one which, while providing for various special needs, lists the provision for autism as a distinct category. There are, however, a number of institutions for disabilities and disorders, and it is likely that these contain some cases of autism "hidden" within broader categories of mental disability behavioural disorder.

Both public and private education and medical care exist in Kuwait, and provision for people with special needs is divided among several governmental and other non-governmental agencies. This chapter reviews those bodies whose services are most relevant to autistic children and their families, before outlining the specific provision available for autistic children in Kuwait.

4.2. Background

The government of Kuwait is a constitutional monarchy with executive power vested in the Amir, the head of state. Under the 1962 constitution, the Amir is chosen by and from members of the royal ruling family: the al-Sabah family dynasty that has been in power since 1756. The government is exercised through the Council of Ministers. The Amir appoints a Prime Minister who then recommends other ministers to the Amir for appointment. The Council of Ministers consists of 50 elected members and 25 appointed by the Amir. This council shares legislative power with the Amir and is generally elected for a four year term.

Women are denied the right to vote and only natural-born, literate, Kuwaiti males aged 21 years or older who can trace their ancestry to pre-1920 Kuwait are permitted to vote. This represents approximately only 15% of the adult population of Kuwait. Clements (1994) states that the judicial system of Kuwait is a dual system based on civil law and Islamic law, with the primary Islamic source being the Koran, which states that

all Kuwaiti citizens are equal before the law in prestige, rights, and duties. Individual freedoms, including freedom of speech and writing, religion,

property, freedom from search and seizure, freedom of movement and choice in place of residence are guaranteed. Equally importantly, all Kuwaiti citizens have the right to an education, as well as freedom to choose their own type of work, assuming it is available.

Education is compulsory in Kuwait for all children for eight years between the ages of 6 and 14. State education is free and is graded into pre-primary ages 4 to 6, primary ages 6 to 10, intermediate ages 10-14, and secondary ages 14 to 18 years. At the primary level, girls and boys are segregated into separate classes and remain segregated throughout secondary education.

4.2.1 Background to Current Cultural Practices in Kuwaiti family life.

Traditionally, the mother of the family sees to all aspects of the child's needs, whilst the extended family also take responsibility for the child and give support for its child rearing. The extended family consists of a mother, a father, aunts, uncles, great aunts, great uncles, cousins, brothers, sisters and in-laws.

Similarly, until the discovery of oil, all babies were born at home where a local experienced *Walladah* (a helper) would assist with the birth, whereas, at the present day, mothers can choose whether or not to attend maternity hospitals or to give birth in their own homes. Once the baby has been born, it is important to state for a non-Moslem reader that a female child remains with her birth family until marriage, and a male child, although he may well stay within his birth family, is seen as an adult by the age of 15 years. Some male children are considered adult by the age of 12 years, depending on the circumstances of the family. For example, if the father is absent from his family, then his eldest son from the age of 12 years will accompany his mother and sisters, should they need to go shopping. It is forbidden for Moslem women to go out alone. For both male and female children, the family are the prime caregivers.

Within Moslem society, the father has a big influence on the children but in a more general way than the traditionally accepted duties of the mother. The day to day basic needs come from the mother and female members of the extended family. The senior male members are more concerned with religious matters and discipline, such as making sure that boys and girls learn to have respect for their parents, grandparents and older people in their families as well as others within their communities. Equally, it is for the father to ensure that his sons are raised with a knowledge of the Koran and the prayer life of the Moslem faith.

Although the next refers specifically to what used to happen fifty years ago it also applies to abled bodied as well as disabled people. There were no schools fifty years ago for children with any disability; therefore, the mother and female members of the extended family were left to look after the child's needs until they died. This could take fifty to sixty years. So during the life time of the disabled child, if the mother died and left the child, the responsibility rested with the father and the rest of the immediate family. If the father died, then the disabled child or disabled adult then became the responsibility of an aunt on the mother's side. Sometimes the father might marry a new wife in order to provide a substitute mother to care for the disabled child or disabled adult. Within the extended family, working from the centre outwards, the responsibility for disabled members of the family passed onto the next closest circle of family members. For example, the centre of the family circle are the parents, then the next circle are the grandparents, aunts, uncles, brothers, sisters, cousins and members by marriage.

If, by chance, none of these family members were alive, then fifty years ago the neighbours in the same locality would take on the responsibility of caring for the disabled child until he or she reached adulthood. Even as an adult, the disabled member of the community would continue to be cared for by the rest of the extended community, each family within the extended community contributing towards the needs of the disabled member. This sense of duty and responsibility comes from the religious teaching in the Koran.

Not many disabled children lived to an old age because of complications during birth or during the early years of childhood, combined with a lack of medical knowledge. In contrast, at the present time, every effort is made to ensure the disabled person is kept physically well. (Fuller details of how this is achieved are given below). In rural areas the development of medical provision at the present time has begun with the purchase of houses in order to centralise local medical provision.

In relation to traditional usage of medicines and doctors today there are the same chemical medicines and professionally trained medical practitioners available in Kuwait as in the Western World. However, traditionally generally, the mother would breast feed the disabled baby as normal but would give him/her some local medicine, such as *Habhaw Maramiya*. (There is no English equivalent). This medicine is made from herbs and special leaves from certain local plants. The leaves are boiled in hot water and then left to cool before being given to the patient. Other plants and leaves are ground up, using two stones being rubbed together. This medicine would then be administered with

a spoon plus a drink of water, or just simply administered as a powder into the mouth. This practice is still used today by many families who prefer to use natural medicines rather than pills and potions bought from the doctor or prescribed by the hospital.

Generally, these natural Arabic medicines, such as *Heshhash,* (the researcher does not know the English equivalent) were and are still used to make the disabled person much quieter and more easily controlled. Likewise, other plants, such as *Haksher*, were and are used to bring down temperatures and to treat *Bumber* (flu type symptoms with high temperatures); *Innab* (Scarlet Fever*); Lisan althor* (German measles) and similar diseases, such as *Taranjabeel* (Jaundice). Such traditions are extremely difficult to stop or change. There is much resistance to stop using established methods of home remedy medication prevalent throughout the Middle East, although young mothers are more inclined to follow the fashion set by the Western World.

Within the context of the Mosque as well as the Moslem home, all disabled people were and still are treated exactly equally to able-bodied persons. In many cases the love and care given to them was and is even more than that given to children and young adults who were or are not disabled. This has caused problems for some who have become very spoilt, resulting in the fact that they do not have any understanding of the word "No". Therefore, they insist and behave badly to get their own way in all things. Whilst it is acknowledged that this is not good for the disabled person, it is very difficult in the Islamic religion and community to be unkind to such persons, even if it is for their

own good. This aspect of the Islamic religion can contribute to some of the challenging behaviours displayed by autistic family members.

The British Hospital was established 1938, and the American Hospital was established a short time after the British Hospital. Each one developed along different lines. The British Hospital was used for more general medical aspects until it was superseded by Kuwait Hospitals in the 1960s. The American Hospital developed as a much more specialist medical facility. It, too, was superseded by the development of Kuwait Hospitals in the 1960s after the discovery of oil in Kuwait brought the revenue to fund extensive socio-economic development projects. Since them, high quality medical provision has been available to all Kuwaitis.

With the opening of the American Hospital came Western ideas and practices in regard to the ways in which disabled people were to be medically treated. The medical staff of the American Hospital would not entertain the traditional, religious or family influences. For example, traditionally, family members make a special herbal massaging lotion to calm children (whether disabled or not) when they are having tantrums. Over centuries, it has been found that the gentle massaging of the child's body helps to calm down the anger and frustration that has built up. Traditionally, the lotion was produced by hard boiling ten eggs in their shells and then removing the yolks. These were re-heated until the yolks turned to oil. After cooling this oil lotion was then used to massage the damaged part of the body. Alternatively, almond oil was used to massage the disabled person. Massaging had a twofold effect. Firstly, the limbs were exercised and this meant

an easing of the pain. Secondly, the effects of massaging the body helped to bind the family to the disabled person, whilst effecting a quietening of his/her anger. Making the disabled person comfortable assisted both him/her and the family to support each other to tackle the problems associated with the particular disability.

In present times massaging is not recommended in hospital or by many doctors, although it is still a major form of treatment of tantrums in many households. Massaging has been superseded by present day ideas of exercises and distracting children in a tantrum.

Thus, on the whole it would be true to state that in Kuwait, the mother and child rearing situation is similar to established traditional methods, but with lots of professional support as per the Western World. For example, if the mother is working (this is a new phenomenon in Kuwait as, traditionally, once a woman married she did not take up any employment), the child stays with the mother for two months whilst the mother is on full salary. Then, the mother can opt to stay at home for a further year, but without salary. When she returns to work, a wide range of professional support systems is in place. Female gynaecologists, female social workers, paediatricians, paediatric nurses, physiotherapists, and counsellors for both parents and for the family, if they feel it is necessary, are available.

If the mother or parents do not have an extended family to support them, they will often employ a housemaid to care for the disabled child. Moreover, there are many

nurseries for all children, and where disabled children are cared for whilst the mother or father is out at work. But by school age, unlike the Western world, all disabled children are educated in Special Educational Needs Schools. There is no integration of physically, mentally or social behavioural disabled children into mainstream schooling. Within these schools much money is provided so that a special programme for each individual child is tailor-made in order to educate each individual to his/her potential. This funding is provided by the Government of Kuwait with no restriction on the amount to be spent. (Yet, interestingly, from the results of this study, most parents perceived that there was a need for more Government input, especially in rural areas).

For instance, if a disabled child or a disabled person requires specialist medical treatment or specialist operations, they are sent to the United States, or Europe for treatment, free of charge. The Kuwaiti Government pays all expenses, even down to the cost of the taxi or ambulance to Kuwait Airport. The patient and his/her parents fly first class and whilst in hospital and convalescence outside Kuwait, there is no cost to the person or their family. This continues for as long as it is needed, even if it is a two year period. Once the patient arrives back in Kuwait, their needs are catered for free of charge. Thus, if the family find that they need money to pay for specialist treatment such as physiotherapy, Kuwait has an extensive Welfare System. Because Islam teaches that each individual is to be respected for who he or she is, there is no stigma attached to having a disabled child or a disabled member of the family.

Today, as stated, many young Kuwaiti mothers use chemical based medicines from the doctor. And further, today, there is generally a clearer appreciation of and understanding of the needs of disabled people. This has resulted in a high quality of medical provision. It is recorded that with the increase in medical provision there has been an increase in medical needs. This may be accounted for by the heightening of awareness of illnesses and early diagnosis of general as well as severe illnesses and diseases.

However, the educational provision has not kept pace with the medical provision. In general, disabled children once of school age are entertained and kept occupied or contained within the school environment, as opposed to being given appropriate opportunities to reach their potential, though this is the case, whilst there are inevitably exceptions to every rule.

In regard to autism, there is an Early Intervention Centre for the children with Special Needs. This centre is funded, run and organised by the State of Kuwait, Ministry of Social Affairs and Labour Social Welfare Sector. This, then leads onto a brief resumé of Kuwaiti Governmental and other bodies provision for special needs.

4.3 Governmental and other Bodies Catering for Special Needs

Special education is administered through the Ministry of Education, the Ministry of Social Affairs and Labour, and the Kuwait Society for the Disabled. According to the Ministry of Education (1992) provisions for individuals with handicaps include boarding schools, schools in hospitals, schools in other institutions, day special schools and classes

in ordinary schools. Such schools for individuals with handicaps have a separate curriculum, with some focus on vocational development.

In Kuwait there are two specially designated public school systems: one for males and one for females, for children with special educational needs whose IQ scores range between 70 and 50. In general, the pupils in these schools study an academic curriculum that has been adapted from the primary level of the general educational programme. After this, pupils are transferred to vocational rehabilitation schools for five years or so. Male pupils specialise in leather-work, upholstery, or bamboo-work. Female pupils specialise in tailoring, dressmaking, bookbinding or embroidery.

Provision for special needs in Kuwait is divided among a number of governmental and other bodies. The roles of those most relevant to this study are outlined below.

4.3.1. Governmental Bodies

(i) Ministry of Social Affairs and Labour:

Through its Disabled Welfare Department, the Ministry provides residential medical care and rehabilitative education for both children and adults. The Disabled Care Homes cater for the severely mentally or physically disabled, while the Social Rehabilitation Centres serve some 275 people (of all ages) with mental disabilities. Information from the Department makes no specific mention of autism, so it is not known how many, if any, of the children cared for in the Department's homes are autistic.

(ii) Ministry of Education:

In 1992, the Ministry's Department of Special Education provided care and rehabilitation for 1,339 people with special needs, as follows:

Mental disabilities	762
Hearing impaired	295
Blind	69
Mobility disabled	213

No specific provision for autistic children was listed, though again it is possible that the schools catering for mental disabilities contained some cases of autism. The Ministry has financed the staffing of the new Kuwait Centre for Autism, inaugurated in September, 1995 (see section 4.3). There are no more officially published up-to-date data available at the present time, although agencies did provide their own up-to-date data on request.

(iii) Ministry of Public Health

The Ministry is concerned with early detection of disability, diagnosis and treatment, through a number of centres, divisions and hospitals, including:

Maternity and Child Health Division

Developmental Medicine Unit

Psychological Rehabilitation Division

Speech and Hearing Treatment Centre

Schools Health Division

Such services are provided free of charge to all, whether Kuwaiti nationals or others.

4.3.2. Non-governmental Agencies

(i) Kuwait Society for the Handicapped:

Kuwait Society for the Handicapped (KSH) was established in 1971 by a group of Kuwaiti philanthropists, to help children with multiple handicaps or behaviour anomalies, particularly those not accepted by the Governmental institutions. The Society aims to provide medical care and education, to give financial and moral support to families of children with special needs, and to co-operate with government bodies in the provision of care and information.

Much of the Society's funding is from charitable donations, although an annual governmental grant (currently KD. 100,000 p.a.) is received from the Ministry of Social Affairs and Labour. The Society's headquarters in Hawalli provides residential care for some 76 children, while a further 72 undergo a day-care programme. Most of these children are multi-disabled. In addition, day care centres have been established in Hawalli (1987) and Al-Jahra (1993), to cater for children with developmental disorders, including autism. Together, these two branches cater for around 150 children.

Children are referred to KSH by doctors, parents and special schools. Before admission, the child is assessed by a multi-disciplinary team including doctor, social worker; psychologist and physiotherapist, so that an individual programme can be planned to meet the child's needs.

The Society's literature reports that a special pilot programme for autistic children has been established as a research project in the Society's Day Care Centre. The Society also reports that some improvement in the children's behaviour has been observed.

However, no details are given. Of 628 children registered with the Society for counselling and therapy, 47 (7%) are autistic.

(ii) Al-Najat Charity Society:

The society provides financial assistance to needy families and supplies aids for the disabled, either free or at substantially reduced cost.

(iii) Special Endowments: In accordance with the importance attached in Islam to charity and social welfare, institutions and facilities for those with special needs are sometimes endowed by wealthy philanthropists, or by public subscription. Even state facilities may be partly endowed in this way, as will be outlined later.

(iv) Private institutions:

Private sector educational and medical facilities make provision for those with special needs. An example is the Khalifa School for Children with Special Needs (see next section) which caters for a wide range of disabilities, including autism, cerebral palsy, Downs syndrome and various learning disabilities.

4.4 Special Education for Autistic Children

As indicated in the previous section, despite the concern of governmental and other non-governmental bodies to provide for those with special needs, the situation with regard to autism is unclear and specifically designated provision for this disorder is limited. The researcher found that there were only two special schools which made specific provision for autism:, i.e. the Khalifa school, and the Kuwait Centre for Autism, a newly established government institution. In this section, the limited information available regarding these two institutions is presented.

4.4.1. The Khalifa School for Children with Special Needs

The Khalifa School, established in 1988, is a non-profit private school. It started as a small nursery school for special needs children. During the Iraqi invasion in 1990 it had to close down, but it was re-established in October, 1991. Although there is a government institution catering for the educational needs of special children, what makes the Khalifa School distinct is its multi-national and child-centred approach. The staff, as well as the students, come from various parts of the Middle East. However, a large majority of the students are Kuwaiti nationals.

One of the problems of the Kuwaiti Society is that there is no state-run institution which can accommodate a child with multiple disabilities. Thus, the Khalifa School is the only educational institution which accepts and provides for the educational needs of such children. It maintains an open-door policy of accepting children, regardless of the severity of their disability. The Khalifa School, therefore, provides specialist services for children with mild to profound mental disabilities. Likewise, although fees are payable for the school's services, approximately 30% of pupils are non-paying. The Khalifa School accommodates 190 students. Of these, about 33% are autistic (see Table 4.1), making autism the second largest category dealt with in the school.

Table 4.1: Number and Type of Children at the Khalifa School

	Autism	Downs Syn.	Cerebral P.	Mental Health/other disabilities	Totals
Boys	51	19	22	37	129 (68%)
Girls	12	12	10	27	61 (32%)
Total	63 (33%)	31 (16%)	32 (17%)	64 (34%)	190

(Source: Khalifa's Leaflet 1995, Kuwait.)

Like any other institute of special education, the Khalifa School aims to provide relevant learning environments to teach each child to fulfil his/her potential emotionally, socially and academically, utilising his/her fullest abilities in order to become as independent living as possible, and to acquire basic relevant adult life skills. The main emphasis of the school curriculum is teaching social and life skills, and providing equal opportunities of education to children with learning disabilities.

One of the distinctive features of the school is that it provides facilities for the training of Kuwaiti nationals, with a view to enlighten the Kuwaiti society in the recognition and acceptance of special needs children as part of their own immediate community. To achieve this aim, the school organises a number of community activities to enhance public awareness, and regularly appears on television in an effort to flag up its work.

The Khalifa School believes that each child has the right to be educated. Therefore, its teaching programme is based on developing individual teaching goals through collaboration between parents and teachers. The school provides consultation and assessment from a multi-disciplinary team of specialists, and an individual education programme is developed for each child. The three fundamental steps of ascertaining which curriculum is operated as follows:

(i) A developmental assessment is carried out of the child's skills and deficits deficits various areas of functioning.

(ii) On the basis of this assessment, teaching strategies are determined in order to achieve short-term objectives and long-term teaching goals.

(iii) These objectives are implemented with individualised educational programmes and specific teaching activities.

To support the above, the Khalifa School follows a specific language training system, which is based on makaton symbols. The aim of this system is to enable the child to communicate effectively, according to his/her potential. And recently the school has introduced a new educational programme which places full emphasis on Arabic, as a spoken language.

In addition to helping each child to fulfil his/her potential, the school aims to support families. Parents' Support Group meetings are held, where parents can meet and discuss their difficulties in coping with the specific and special needs of their own child/children. By sharing their experiences it is intended that the parents' support group becomes a self supporting group. The school aims to keep abreast of international developments in the field of special education, so for example, it meets these by sending staff on exchange programmes, and inviting international lecturers.

Unfortunately, most of the school's teaching materials and equipment were destroyed during the Iraqi invasion of 1990, and many facilities have yet to be replaced, though the school re-opened in October 1991.

4.4.2. Kuwait Centre for Autism

The centre is the first institution in Kuwait to deal exclusively with autism. It was established in January 1995, and was officially inaugurated in September 1995. The establishment of the centre reflects the Kuwaiti government's awareness of a gap in special needs provision, as well as the pressure being exerted from families with autistic

members, for whom suitable provision has, until now, not been available. Much of this pressure has been of a religious nature, as Islam emphasises the need to support and help those who are less fortunate, as well as the need to share wealth. Kuwait in this respect is following the lead of Saudi Arabia, which recently established a pioneer centre for autistic children in Jeddah.

The Kuwait Centre for Autism is under the direct supervision of the Directorate-General of Religious Affairs, which funded the building of its accommodation. The staff are appointed by the Ministry of Education, whose intention is that whilst the staff will have initial specialist qualifications, it will be absolutely essential to ensure on-going professional development and up-dating in-service to keep abreast of current thinking in the area of autism. The furniture, equipment and money have been donated by various individuals, companies and organisations in order to get the Centre established and maintain its momentum. This fund-raising, and requests for donations will continue, as voluntary work in Kuwait society will be supported, whether through deed, time or money.

The main objective of the Kuwait Centre for Autism, is to put forward an educational programme which will address the needs and facilities of autistic children's behaviour. This will be achieved by creating an educational environment which enables the children's parents to recognise, understand, share and overcome their anxieties, experiences, and problems. By motivating the autistic children to maximise their educational achievement, taking into consideration individual differentiation, it is the fundamental intention of the centre to endorse their profound belief in individual educational entitlement. Ultimately, supporting the children's own interests and abilities will form the basis for their future, i.e. the possibility of purposeful rehabilitation and integration into Kuwaiti society.

Running in tandem with the above aims, it is hoped that staff and other Kuwaiti academics will be able to prepare and publish research and studies relevant to Autism. Also, it is anticipated by the Kuwaiti Government that there will be cross fertilisation from this academic research and the continuous support and in-service training for the teaching staff, in line with world-wide developments in the field of Autism and other disabilities. It is intended that every effort will be made to ensure the full co-operation between the Kuwait Centre for Autism and other similar international centres.

In order to reduce the cost of running this Centre, only qualified Kuwaiti manpower will be deployed. This is necessary not only to save the cost of employing expatriate experts, but more importantly, to encourage social integration between the children and their teachers and the wider community, as spoken Arabic as a language will be its main thrust. With the emphasis on Arabic as a spoken language, it is essential to use Arabic speaking staff. Hence, it is anticipated that the centre will be well prepared academically and technically to serve this purpose.

As it is imperative that all agencies and all parents are fully involved in the training programmes for the autistic children's behavioural difficulties, the centre will provide relevant training programmes for parents and families, and any member of the wider community who expresses an interest etc. By so doing, it is hoped to achieve some kind of continuity and correspondence between the school programmes of study and the home programmes of study. Likewise, local, national and international conferences will be organised with a view towards heightening the academic (national as well as international), and the public awareness and knowledge of the problems of autistic children and the problems experienced by their families.

The principal aim of all concerned with the Kuwait Centre for Autism will be to focus on the problems of each individual; having identified his/her problems every effort will be made to develop an individual programme to encourage realistic social and life skills. It is hoped that this will encourage the children to establish reasonable social relationships in preparation for their integration and acceptance in the wider community.

4.4.3 Montessori School

This private school takes children with autism and works on the Montessori learning principles of encouraging each child to develop his/her own interests using a wide range of media and resources. Because of this there is very little formal school curriculum. The staff have no specialist training in dealing with Autism. The head teacher explained that the few autistic pupils in her school were "contained". By this she explained her staff did their best to handle the outbursts of challenging behaviour from the autistic pupils. When such behaviour as head banging or biting got too much for the staff to handle the pupils' parents were asked to collect them for that day.

The head teacher informed the researcher that because the abilities of the autistic children were very low the staff were not able to develop any interests. They were instructed simply to attempt to keep the autistic children clean and ensure that they did not harm themselves or other pupils at the school. If the autistic pupils showed interest in an on-going activity such as music or painting, the staff were instructed to encourage them to participate.

4.5 Summary of the Chapter

It is only recently that autism, as a distinct category of disorder, has been specially provided for in Kuwait, and even now, very little specific provision exists.

The limited provision that exists, is equally divided between government and private bodies. A noteworthy feature is the extent to which provision for autistic children still depends on charitable donations, although the Kuwait Government are making yearly financial provisions to support the initial start in this area.

Also, very positive attempts are being made to keep abreast of the latest developments in ways in which to devise purposeful support for autistic children. This can be seen in terms of a multi-disciplinary team of doctors, psychologists, therapists and educationalists co-operating to design and deliver individually-tailored programmes for children with this special need. As this work is still very much in the pioneering stage for Kuwait, based on the estimate that some 500-700 cases of autism may exist in Kuwait, it is reasonable to state that even with the opening of the new centre, and the Khalifa School, specialised provision exists for only a small proportion of the total number. However, with government backing there is a strong anticipation that much diversity and development in this area will be achieved within the next five years.

The next chapter will give a description of the nature and aims of the field study, where justification of the research design, plus its implementation will be detailed. Also, a statement of the reasons why a questionnaire experimental design was used in preference to other experimental designs will be given.

Chapter Five

THE NATURE AND AIMS OF THE FIELD STUDY

5.1 Introduction

The objective of the current chapter is the description and justification of the research design. The chapter begins with a brief discussion of the need for this field study, and then moves on to a statement of the reasons why a questionnaire design was used in preference to other designs.

A questionnaire in the form of ***Survey Questionnaire of Families and their Responses to Behaviour Problems Related to Autism*** was administered to the cohort of families, where each respondent was asked for his/her opinions related to the stress factors and elements affecting their particular family. An array of standardised research double checks was implemented in order to attempt to cross-reference respondents' responses during the completion of the questionnaire. During the administration of the questionnaire, an audio tape recording of the interview was made in order that the researcher could double check that each element of the questionnaire had been clearly understood by the respondents.

Because questionnaires are intrusive into the lives of the respondents the procedures implemented to address ethical issues are detailed in sub-section 5.5.2. This was done to ensure confidentiality, anonymity and non-traceability of all respondents.

5.2 Rationale

To-date, rigorous experimental comparison within and between family members with an autistic child, has not been undertaken in the country of Kuwait.

Study was, therefore, needed to find out the effects of autistic children's behaviour on the parents. This necessitated collecting data for each parent's perception, i.e. *within* each research situation to ascertain the similarities and the differences in response to the behaviours displayed by the autistic member of the family. Having obtained answers to this, there was a need to collate the dataset of each parent dependently, e.g. *between* each respondent comparatively, to answer the question: Is there any significant difference of impact of the behaviour of the autistic member between the various parents listed? This would allow the researcher to directly research the impact of the displayed behaviour rather than simply just the perceptions of the parents of the family at the time of the study, hence the need for this study.

The foregoing Review of Literature outlined the theoretical background and current debates into the various aspect of research into Autism in general, and the effects upon parents. This provides a rationale for this study that it is important to collect and collate data related to the provision of support for autism in the country of Kuwait.

It is evident that there is a need to determine whether and to what extent the impact of autism on family members affects the dynamics of the family and to what degree. The studies mentioned in Chapter Three, indicate the possible existence of serious family rifts and breakdowns of marriage because of the impact and the demands an autistic child places on the mother in particular. It is desirable, therefore, to highlight potential problems using field study questionnaire research methods. These are, therefore, detailed below.

5.3 Statement of the Problem

With the upsurge of interest in autism in Kuwait it is important to substantiate the impact of autistic behaviour on parents, the family and the extended community. All are affected by such behaviour. The problem this study has set out to investigate is not simply the perceived problems as single and separate issues, but rather, their inter-related similarities and differences and how these link to providing positive support for the autistic family parent(s) as well as providing relevant support to each family member affected by these behaviours.

5.4 Aims and Objectives

The aims and objectives of this study are to explore and investigate the impact which autism has upon parents in the country of Kuwait, to collect raw data related to the similarities and differences of perceptions and experiences of specific parents, to relate the study findings to some of the studies done in the western world.

By doing this it was hoped to substantiate or reject the claims made by western research on the impact autism has on the family.

5.5 Research Design

5.5.1. Background

After considering the various different methodologies for collecting data related to the incidence and impact of autism on the family, it was decided to base this study on questionnaire techniques. Because it was necessary to translate the information generated by the questionnaires, a quantitative and a qualitative analysis of the data was essential. Strauss and Corbin (1990) suggest that qualitative methodologies provide enough flexibility for understanding to emerge through the representative themes identified in the analysis of the data.

The principal reason for deciding upon a questionnaire and qualitative data research is that it is a more common research design in non-mechanistic types of studies. The principal purpose of this study was to directly test the perceptions of each family's parents related to the impact the behaviour of the autistic member was having on their lives. This was to be demonstrated by a comparison of similarities and differences in the responses given in questionnaire situations.

Moreover, the data is quantifiable and allows for little deviation, particularly when a restricted code of answering exists. It allows the researcher to limit the areas to which the responses are required, and to make broad and reliable generalisation from the information collected. Further, as it was necessary to informally interview the respondents to ensure that they fully understood each item on the questionnaire, and, although, this was not in strictly the same stringent research procedure as an interview technique research would be conducted, the researcher believes a definition of interviewing should be given.

Fletcher (1988, p. 9) defines an interview as *a purposeful conversation*, whereas Breakwell (1990, p. 1) advocates that interviewing *is used in many contexts – anywhere, in fact, where people wish to get and give information in an orderly fashion so the interviewer can focus on what is important to the interviewee and hear it expressed in their own words.*

5.5.2 Ethical issues

Because all questionnaires are so intrusive into the lives of respondents and in adherence with the University of Hull code of ethics for research, the researcher ensured that all respondents knew their rights. Further, as Morrison (1996) emphasises that

methodological rigour is an ethical, and not simply a technical matter, thus respondents have a right to expect reliability and validity in this study. To comply with these requirements, it was ensured that each respondent clearly understood that

- the completion of the questionnaire was done with their informed consent
- they had the right to withdraw from the study at any stage whether the questionnaire was completed or not
- the respondents were assured of total confidentiality, therefore, no harm could come to them or their families
- further guarantees of anonymity and non-traceability in the thesis was given
- every care had been taken to be sensitive to the content, structure, bias of responses required in the questionnaire
- should there be any question or aspect of the administration of the questionnaire that a respondent considered to cause offence, or be intrusive, misleading, biased, misguiding, irritating, inconsiderate, impertinent or abstrusive, that he/she had a right to refuse to answer the question or withdraw from the study, without any comeback, embarrassment, or coercion being exerted by the researcher.

5.6 Scope and limitations of the study

5.6.1 Threats to the validity of the Study

External validity is defined as the extent to which the findings of experiments can be applied to particular settings. The following is a description of the questionnaire and its reliability and validity. Good and Brophy (1990) state that 'at the most basic level a test is said to be valid if it measures what it is supposed to measure' (p. 689).

The threats to the external validity are likely to limit the degree of confidence to which generalisations can be made from the particular experimental conditions to other

populations. This indicates that, a researcher must always question the extent to which his/her results are representative and whether results obtained from one set of pupils can be generalised to the population as a whole. In other words, the results of this study can only be generalised beyond the confines of this particular study once it is externally valid. Campbell and Stanley (1966, p.14) have identified six factors which can jeopardise the external validity of experiments and/or studies. These are failure to describe independent variables explicitly; lack of representativeness of the target population; Hawthorne effect; inadequate operationalising of dependent variables; sensitising to experimental conditions and interaction effects of extraneous facts and experimental treatments.

All efforts were made to lessen the threats to the validity of the study by ensuring that each respondent clearly understood each question in the questionnaire. This was supported by the researcher audio taping the interview. Further, the researcher ensured that he was not a stranger to the cohort. However, because of the lack of statistical evidence as to the exact incidence of autism in Kuwait, caution must be exercised when attempting to generalise the results of this study as they may not be a true representation of autism in Kuwait. The results are a true representation of the diagnosed autistic family members in the three schools.

Lincoln and Guba (1984) suggest that in qualitative research, dependability is the parallel construct to reliability in quantitative research. A dependability limitation relates to the willingness of each participant to be openly critical of services. That is, were they acting as polite guests when completing their questionnaires? It is impossible to know the Kuwaiti cultural assumptions regarding being openly critical in social situations. Nor is it possible to know how much each participant did or did not adhere to cultural assumptions. Every effort was made to attempt to ensure that dependability was achieved,

by the researcher clarifying understanding of the questions and listening to the audio tapes.

Further, Guba (1998) and Lincoln and Guba (1984) advocate that many reject quantitative research labels and underlying constructs of internal validity, external validity, and reliability, choosing instead to create new terms more specific to and reflection of issues in qualitative research, although most scholars, however, see the need for reliability and validity issues to be addressed carefully in qualitative research. Lincoln and Guba's (1984) terms are used most often in qualitative research as they talk of trustworthiness as the general issue, with creditability (internal validity), transferability (external validity), dependability (reliability) and confirmability (objectivity) as aspects of creating trustworthiness of the data.

Also, regarding the reliability of the instruments Van Dalen (1979) states that 'the results obtained from a sample of subjects is only as good as the instruments used to collect that data. Therefore, it is of the utmost importance that instruments are reliable, objective, and valid, as well as suitable for the job they have to do, so the information and reports from the investigation are both correct and clear' (p. 135).

5.6.2. Scope of the study.

There are limits to this study which can limit its validity. In addition, there may be cultural effects because the sample being used is entirely from Kuwait, so it may not be possible to generalise the results to the western world. This limiting of the external validity power of the findings will, however, apply to most Islamic countries. The advantage of the study protocol was that the respondents were readily accessible. They could react positively in familiar, comfortable environments with known peers and

known established routines within the centres. Therefore, this familiarity with the situation could possibly reduce anxiety effects on the results, and the desire to give simply what is perceived as the 'correct' answer. Also, the researcher's doing all the travelling allowed for greater flexibility of access and caused less disruption to the respondents and the autistic family members. It is argued that field studies do have validity, despite the obvious disadvantages and difficulties outlined above. In this case the balance of advantages was considered to be better than the disadvantages.

5.6.3 Significance of the Study

Briefly, this study's aim is to investigate the impact of autistic behaviours on families. This is the first time any such study has been conducted in Kuwait. Therefore, the findings of this study are likely to generate useful discussion on ways of identifying and supporting families with autistic members. Further, it may usefully serve to highlight the stresses and stress related problems associated with such situations. A general awareness of these problems and the behaviours of autistic children could benefit the general populace of Kuwait.

This study aims to contribute towards both of these endeavours. In addition to these, it hopes to answer the question, are there similarities and differences between the experiences of Moslem families and those of non-Moslem families, both in Kuwait and in the western world?

5.7 Summary of the Chapter

This chapter has described the purpose and rationale for selection of the questionnaire research techniques and the informal interviews implemented in this study. The usage of questionnaires was discussed and evidence put forward as to their validity. The above background then leads on to the next Chapter where a detailed methodology is given.

Chapter Six
METHODOLOGY

6.1 Introduction

The methodology for this study is described and explained, along with the procedures used in carrying out the investigation and achieving its aims. There follows a description of methods used to collect data, plus the sample size, and administration of questionnaires.

Also, this Chapter considers the need to identify the similarities and differences experienced by the various specific parents to the impact of the behaviour of the autistic family member.

6.2 Study Location

The families of autistic children who reside within the country of Kuwait were selected as the main objective of this study is to obtain data and information related to the incidence of autism in Kuwait and the impact it has upon the family. The children had all been diagnosed at their local hospitals and/or private physicians, using only DSM–111-A and DSM–IV criteria. Thus, some degree of continuity may be presumed in respect of diagnosis.

6.3 Time Scale

The total time scale of this study was over one academic year. This was because of the need to have an independent observer, plus a mini-pilot study to validate the questionnaire and to gain an agreed format for the procedures. Further, there were

difficulties in gaining access to families with autistic children who were Moslem, but who were not to be used in the final study.

6.4 Sample

A general letter of invitation, which described the intended research, was sent to families reported by the specialist centres/schools. 100 questionnaires were sent out and some replied stating that because of family wishes or other constraints they were unwilling or unable to assist in this instance. 52 responded positively, making a total of 52 out of 100 replies (52%).

Those 52 families were used. At the commencement of the study the ages of the autistic children involved ranged from birth to 22 years 3 months, with a mean of 13 years 4 months. There was a total of 44 male autistic family members and 8 female autistic family members, making a joint total of 52. Further, the number of members in each family, who were participating, was recorded. As can be seen all the families of this sample were those who had been referred by the specialist schools and where the children/young persons with autism had received a diagnosis according to the criteria of the DSM series.

6.5 The Research Instrument

The instrument chosen for this study was a questionnaire. Bell (1993, p. 75) advises that a well-designed questionnaire is one that can produce the information which is needed. It should be designed to be relatively easy to administer, analyse, and interpret, so that it can provide feedback on perceptions of the issues. The procedures adopted in constructing and refining the questionnaire are explained below.

6.5.1. Questionnaire Construction Process.

Since the content of the questionnaires required for the study involved views and opinions as well as facts, the researcher conducted a search of current literature related to questionnaire design; for example, Shavelson and Bolus (1982); Marsh and O'Neill (1984); Allen *et al* (1980); Gibson (1988); Simpson and Troost (1982), and Simpson and Oliver (1988). The procedures followed in the construction of the questionnaires were essentially those suggested by Oppenheim (1966), who states that 'a questionnaire has a task to do, its function is measurement, therefore, the specification should clearly state in the aim the variables to be measured' (p. 22). Therefore, every effort was made in the design stage to ensure that it involved listing the specific aims and objectives of this study and relating each question to these objectives. This was to comply with Oppenheim (1966) and with Cohen (1989) who point out that 'a good questionnaire should be easily understood, short, uncomplicated, reliable and valid" (p. 82).

If a questionnaire is designed for ease of answering by the respondents, it gives them an opportunity to voice concerns without too much effort. Bell (1993) advocates that through implementing the above suggestions it is possible to achieve a good accurate response rate, because respondents will find the format of the questionnaire easy to understand; its content will be of importance and relevance, and therefore worthwhile answering. Moreover, Oppenheim (1992, p. 48) states that everything about a questionnaire should be piloted, therefore, the researcher decided to conduct a pilot study.

In construction of the questionnaire, care was taken that the questions should be framed in such a way as to obtain the necessary information without unduly influencing the respondents. In this regard, Evans (1965) argues that 'statements on questionnaires collected through investigation must be relevant to the specific objectives of the investigation' (p. 2). Oppenheim (1966) states that 'a questionnaire is a scientific tool and

therefore must be constructed with great care in line with specific aims and objectives of investigation' (p. 22).

6.5.2 Validation and refinements

To ensure reliability and validity, the researcher gave a copy of the Autism questionnaire, with a letter indicating the nature and purpose of the study, to four academics with experience in questionnaire research. They were asked to respond to whether the items in the questionnaire were suitable for each scale. These specialists were asked to assess the questionnaire in the following aspects.

* to make an assessment on a scale of 5 for each item, that is, extremely important, important, moderate, fairly important, and not at all important.
* to suggest any additions or corrections for the items, which could be considered important to the present study.
* to make any other suggestions which might be helpful for the present study.

The specialists' responses in relation to the list of the above aspects were classified into five levels according to items' importance and then weighed as follows:

* extremely important = 5
* important = 4
* moderately important = 3
* fairly important = 2
* not at all important = 1

The data were analysed by using the Mean. Therefore, any items with a mean below 5, were removed from the scales. All items in the scale that scored approximately 5.0 or above were retained in the scale. The researcher then analysed the comments and notes of the referees and re-arranged and corrected the items according to their recommendations.

After these changes the researcher discussed and double-checked all the changed statements with the colleagues noted above. All these procedures were taken to ensure that the *Survey Questionnaire of Families and their Responses to Behaviour Problems Related to Autism* could have a sound validity rationale and that the researcher was not making fine distinctions in priorities, which might be too much for the respondents to understand or make.

Since the questionnaire was administered with oral interview support the researcher also applied the advice of Jones (1985), which is detailed below, as validity checks on his research.

Jones (1985) details Hyatt's suggested first step of familiarisation with the data, so this was conducted; that is, the researcher and an independent observer listened to a random selection of recordings of the oral procedures. This ensured that both were familiar with the content of this random selection, and that an acceptable consistency of format had been adhered to. In this study, no biased influence from the researcher was detected.

Similarly, Jones (1985) details Hyatt's second step, that is coding and categorisation of the data, this was used in order to test for trends and similarities of

verbal responses and written responses. Coding is whereby the data is assigned a code number to each answer. In this questionnaire it was post-coded, i.e. done after the administration of the questionnaire. Categorisation is whereby questions with similar general content and rationale are placed together after the administration of the questionnaire to inform all aspects of that particular factor. Hyatt's second step was used because the researcher had conducted all the oral sessions, and because the respondents in this study were being asked to relate their personal experiences, ideas and thoughts. Reflections and/or discussions were deemed relevant to this study.

Further, in order to assess the reliability of the analysis of data similar to that being collected in this study, LeCompte and Goetz (1982) suggest that an independent observer reliability and consistency check should be conducted. They felt this was an important procedure when more than one interviewer had been used during the period of collecting the data. Whilst only one person conducted the oral procedures in this study, the concept of checking reliability was considered to be very relevant. LeCompte and Goetz's (1982) idea was, therefore, adapted and implemented.

The four academics were also asked to comment upon the listed ethical issues in sub-section 5.5.2 above in order to ensure that the researcher had not omitted any important aspect.

6.5.3 Pilot Study

An initial reading of existing literature on questionnaires made clear the importance of a pilot study, based on the argument of Oppenheim (1992, p. 48) and Hoinville *et al* (1987), who state that 'the creation of good questionnaires does not have to rely solely on the researcher's perceptive. At some stage in the design process the questionnaire should be subjected to a field test' (p. 90). Further, in order to ensure that the respondents do not

attempt to produce the *right* answers and resist answering frankly (the Hawthorne effect), there is a need to pilot the questionnaire. Thus, the researcher designed and conducted a pilot study to increase the reliability, validity and practicability of the questionnaire (cf. Wilson and McLean, 1994, p. 47).

Writers, such as Borg and Gall (1983), Cohen and Manion (1991), and Cohen, Manion and Morrison (2000) emphasise the importance of pilot testing. For example, Borg and Gall (1983) reported that 'every questionnaire must be tested and refined under real world conditions. Even after years of experience, no expert can write a perfect questionnaire' (p. 30-31). The researcher, therefore, administered the questionnaires twice to the pilot samples who were not part of the main research. Both sets of results were recorded for analysis to determine the reliability of the scales.

Because the questionnaire's aims were to identify the extent of the impact of the behaviours of an autistic family member upon the various parents, this experience can be viewed as one of the constraints which the execution of a study in the field must accept. No situations and circumstances in research can be perfect, so as the researcher wished to ascertain similarities and differences of response to autistic behaviour, he had to comply with the advice and expertise offered in the literature when constructing his study design and questionnaire.

6.5.4 Record keeping

The method of record keeping used in this study was by recording the administration of the questionnaires with an audio-tape, and with the researcher recording information and facts, after the completion of the questionnaire. The researcher decided to audio tape the completing of the questionnaire and use the recordings to ensure accuracy of understanding and answering of the questions. The audio tape was seen to be useful so

that the researcher could listen to the responses several times to ensure that important points were not missed by him during writing his own notes. Although not originally the intention, the tape recording was also used to identify recurring patterns and themes using NU*DIST to analyse content (see page 167 for definition). Regarding the questionnaire, the written evidence was tabulated and then analysed.

A colleague was asked to listen to the randomly selected audio-tape recordings, and comment on the consistency or inconsistency of approach by the researcher. He had no prior knowledge of the study. This allowed the researcher and the independent observer to review the procedure, stop the tape and offer feedback with discussion before minor alternations were made to the agreed protocol, which was finally used in the study.

Thus, the standardisation of the questionnaire procedure involved the researcher and the independent observer discussing the aims and specific features employed by Jones (1985).

6.5.5 The Independent Observer

In order to minimise bias, two independent observers were used in this study.

The *first* independent observer, a male colleague, was asked to listen to a random selection of the audio-tapes of the agreed format to verify that it was accurate and that there was no obvious inconsistency or bias before a mini-pilot study was conducted. He had no knowledge of the main study, and had no further input into it after this initial requirement. This allowed for the researcher and the second independent observer to view the procedure, and stop the audio-tape to offer feedback with discussion and debate before minor alterations were made to the agreed protocol that was used in this study.

LeCompte and Goetz's (1982) ideas related to assessing the reliability of the data were considered to be very relevant and necessary to the procedures of this study. They were, therefore, adapted and implemented thus: the *second* independent observer, a male who responded to a locally placed advertisement, prior to the commencement of the study, was paid on an hourly basis. The researcher and this independent observer read, discussed and agreed a mutual understanding of the rationale and underlying principles of the questionnaire used. This was to lessen the possibility of researcher bias or deliberate interference.

A mini-pilot study was conducted among Moslem families not resident in Kuwait. This sample was identified by writing to ask for volunteers in Mosques in England, and from the National Autistic Society. The letter of invitation emphasised that only Moslem families would be appropriate. The 25 identified families were then sent a letter explaining the study but only 20 agreed to take part. These families are resident in Birmingham, Manchester, Bradford, London or Leeds. This sample was chosen by their availability, their willingness to participate and by being Moslem with an autistic child.

After this procedure the final format and content of the questionnaire was agreed between the researcher and the independent observer. It is acknowledged that the prior agreement between the researcher and the independent observer could be seen as the researcher's influence creating a bias once removed. However, given the limits of the study and the financial constraints involved, the use of an independent observer in the manner outlined above, was considered reasonable and an appropriate attempt to minimise bias and contamination of the integrity of the questionnaire procedures.

6.6 The Main Fieldwork

6.6.1 Pre-Experimental Period

Prior to the commencement of this study the researcher visited the centres involved on a regular basis. This was desirable as the essence of the study rests on the need for participants to have confidence, and a clear understanding of what was expected of them and an assurance that at all times total confidentiality would be given.

Further, it was important to ensure that each member of the family gave his or her personal opinion and not what they might feel was the expectation of the researcher, or the other members of the family. Family loyalty and adherence to specific family values is a very strong feature in Moslem families, and whilst the researcher would wish for this to continue, he also wished to obtain true individual perceptions, rather than responses couched in feelings of loyalty or guilt about being disloyal to one's family and religion. To increase the likelihood of such responses it was necessary to spend some time giving assurance and building positive relationships with respondents.

6.6.2 Experimental Period

On arrival in Kuwait, letters of introduction were sent to three Special Education Needs centres/schools, namely Ideal Education School, Safat, Kuwait; Khalifa School, Kuwait City, Kuwait and Kuwait Montessori Nursery and School, Jabriya, Kuwait. Each centre/school administrator asked the researcher to submit a brief letter detailing the aims and objectives of his research study. This information was sent together with a letter to parents informing them of the fieldwork, and ensuring total confidentiality and ethical conditions of the study, and asking them to sign a statement of consent for their child to be included in the survey.

The questionnaire which had been designed and developed in the UK was translated into Arabic before being sent to the centres/schools for distribution to parents who agreed to take part in this study. After giving the parents time to familiarise themselves with the questionnaire, the researcher made appointments to visit them to complete it. During these interviews, the researcher asked permission to audio tape the parents' responses so that he could listen a few times to ensure that there was no confusion and that the answers recorded on the questionnaire were exactly what each respondent said during the interview. Each session took approximately 2 hours.

6.6.3 Post Experimental Period

After the questionnaires were distributed and collected, the researcher began to collate and code the information within them. The responses were entered onto blank summary grids, in order to facilitate analysis. Then the total responses for each question were entered. The negative and positive responses were converted into graphs to provide information for answers to the research questions. This raw data was then tabulated onto a computerised spreadsheet where it was analysed using standardised computer statistical analysis packages, such as SPSS, and EXCEL. These packages allow the researcher to ask relevant questions of the data. The results were then tabulated into various tables, figures and graphs detailed in the next chapter.

Further, the researcher used NU*DIST. It was seen as important to identify trends in the usage of descriptors, therefore, NU*DIST was used because it is a software product designed to assist in the process of qualitative data analysis by handling non-numerical and unstructured data. The name NU*DIST is derived from **N**on-numeric; **U**nstructured; **D**ata; **I**ndex; **S**earching and **T**heorising. It is a powerful explorer of data that minimises clerical routine and maximises flexibility through using a range of ways of discovering and exploring the meanings of unstructured data. NU*DIST has flexibility to import or

export data presented in spreadsheets as well as statistical programs along with, for example, unstructured conversational interviews; evidence transcripts; photographs, tape recordings. These were the types of information collected whilst administering the questionnaire. The researcher then word processed all of the questionnaire responses. Each response was then divided into smaller units of text which consisted of one or more phrases or sentences that expressed a distinct idea, theme or concept.

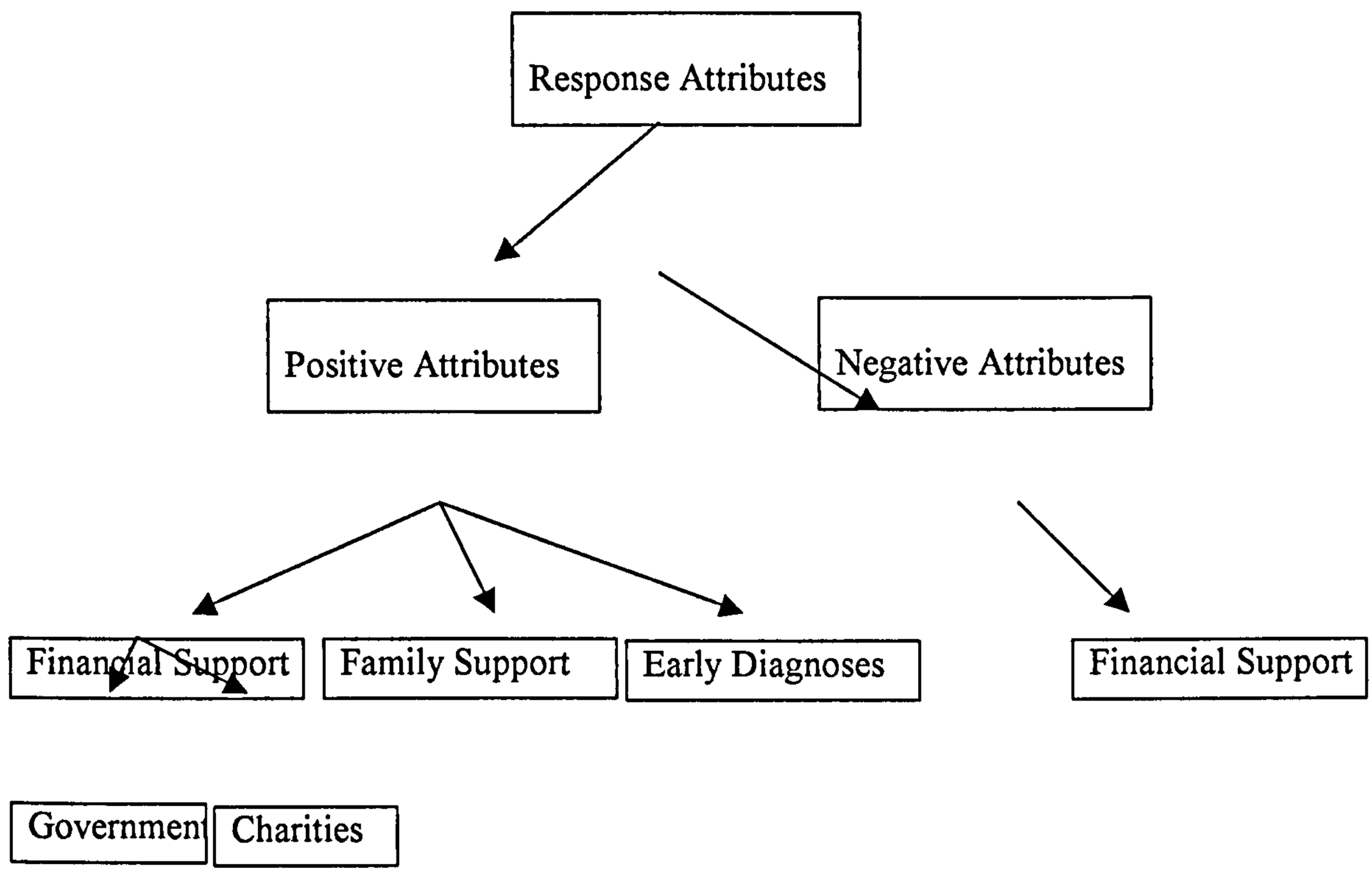
These ideas, themes or concepts were then collected together by topic of conversation, and divided into more detailed subtopics. Each text unit was coded to indicate which topics from the outline it came from. After cross-referencing the subtopics the researcher tallied the frequencies with which each idea, theme or concept appeared in the questionnaire responses text. This was not to quantify the data, but simply to inform the researcher of which ideas, themes or concepts were most frequently used by the respondents.

Westphal *et al* (2000, p.1) states that by using computer packages designed for qualitative data and analysis, a researcher can increase the trustworthiness (i.e. validity and reliability) of conclusions drawn from qualitative research results. This is important because for qualitative text-based research to be meaningful, researchers must understand and trust the research process and results.

In this study QSR NU*DIST version 4 for PCs (N4) was used to analyse the 300 pages of single-spaced transcript of the audio taped questionnaire completion interviews. This particular computer software package was selected because it does not restrict the researcher to any specific methodology for analysis: grounded theory, ethnography, case

study or other qualitative methods. Also, because this package can link with other analysis software such as spreadsheets, statistical packages and graphical analysis tools, the researcher was able to work interactively using text searches to identify patterns, ideas and themes.

Figure 6.1 Hierarchical tree showing how parents response attributes were coded Using QSR NU*DIST N4.



Codes are arranged in an index tree, with a node for each code, text search or index search, thus the researcher used auto coding for demographic information, responses to the individual questions, and participant/nonparticipant status. NU*DIST's trustworthiness tactics are (a) searching for negative evidence and rival explanations, (b) looking beyond dramatic evidence, (c) linking one's findings and conclusions to both

data and theory, (d) conducting coding checks, (e) creating audit trails, and (f) reporting in detail all finds.

Further, Lofland and Lofland (1995) and Strauss and Corbin (1990) emphasise that memo-ing is a tried and true method in text analysis where the researcher reflects on the data or topic at hand, its meaning, and implications for the analysis. Thus, because NU*DIST supports writing memos on both the documents and the codes it was considered to be the best software package at the time of analysing the current study dataset. Equally, Dey (1993, p. 226) suggests that

> by using a computer in analyses of text data instead of retrieving only those databits which support our analysis, we can also retrieve those which are inconsistent with or contradict it. We can produce negative evidence, as easily as positive evidence.

The ability to see all the data sorted by participant status helps the research to see these alternative explanations and patterns, and not just look at the evidence to support an idea or hypothesis. However, it is acknowledged that no matter how efficient and effective computer software packages are, they only facilitate in the analysis of the dataset. They cannot do the analysing. But they do increase the confidence the researcher can have in the results.

So, after completion of the administration of the questionnaire the researcher collated the details of each question in the questionnaire to give a more composite picture of the content of the responses. Then searches were made for similarities and differences in responses, as described above. Thus, by exploring and coding the data it was intended

to discover and explore patterns and themes in the data, as well as construct and test theories related to the review of literature in this thesis.

There were difficulties in using the NU*DIST package when one sentence was found to contain two distinct ideas, themes or concepts. Such sentences had to be broken into two text units, one for each theme, and be assigned the codes for both themes rather than assigning one coding text unit to the whole sentence. This method was found to be very cumbersome and very time consuming.

6.7 Summary of the Chapter

This chapter has detailed the methods used in this field study and stated the rationale to justify their inclusion in its methodology. In order to identify valid and reliable instruments the role of the researcher and that of the independent observer and the instrument used have been detailed along with the procedures used during implementation.

The next chapter presents the results of the analysis of the data collected in this study.

Chapter Seven

PRESENTATION OF FINDINGS

7.1 Introduction

The purpose of this study was to find what perceptions parents had towards the stress and stress related problems they experienced whilst dealing with the behaviours of an autistic family member.

The research findings obtained will be presented in four sections. The first Section 7.2, presents general demographic descriptive data on the sample, in terms of which member(s) of the autistic child's family answered the survey questions, the family's place of residence (urban or rural), the age and gender of the autistic family member surveyed and the number and ages of siblings. The family member's diagnoses and medication are also indicated.

Section 7.3 presents data obtained from the questionnaire, regarding the family member's communicative and self-care skills, their behaviour problems, and sources of help and support. Section 7.7 details criticisms of parental questionnaires. This is followed by Section 7.8. which reports the outcome from analysis of the questionnaires using NU*DIST to explore patterns and themes in the responses of the respondents. Because the researcher wished to compare and contrast the results of the pilot study with the main fieldwork results, these are presented in Section 7.9.

A short summary of the main findings concludes the chapter.

7.2 Description of the Sample

In total, the families of 52 children were surveyed. Data on these children were supplied in 28 cases (54%) by the children's mothers, in 7 cases (13%) by their fathers; and in 13 cases (25%) by father and mother together, and in one case by the mother and a sister. Two respondents did not specify their relationship to the child. The gender and age distribution of the family member, and data on their family background and condition are presented below.

7.2.1 Gender

The majority of the children (46 or 88%) were male. This may reflect the greater prevalence of autism among boys (Aarons and Gittens, 1999), or it may be a reflection of the gender balance in the schools concerned, which raises the possibility that (within the Kuwaiti culture) parents are more inclined to seek help when a child with cognitive, emotional or behavioural problems is a boy than when a girl is similarly affected.

7.2.2 Age

The children surveyed ranged in age from 0 years 0 months to 22 years 3 months, with a mean of 13 years 4 months. Table 7.1 shows their distribution, divided for convenience into four categories: under 6, i.e. those below school age; 6-12, i.e. those in the normal primary school age range, 13+ representing adolescent children of secondary school age and 15+ representing adulthood.

Table 7.1 Age Distribution of Surveyed Family Members (N = 52).

Age	Frequency	%
Under 6	12	21.6
6 - 12	27	52.9
13 +	10	18.4
15+	3	7.1

It can be seen from the table that more than half the sample were of primary school age, while adolescents and young adults together accounted for a little under a fifth of the sample.

Thus, caution would need to be taken when generalising the results of this study as the main thrust of the study is parents and their experiences with autistic children who have not yet reached adolescence. Puberty and the on-set of puberty may have significant effects on the behaviours displayed by autistic children, parallel to those affecting their non-autistic peers, as with adulthood, where specific needs may well be very different from those of preschool and primary age children.

The following table gives a summary of the descriptive information on the family member with Autism by age group.

Table 7.2 Descriptive Information on Family Member with Autism by Age Group (N = 52).

Group	Gender		Mean Age*	Medication	
	Female	Male		Yes	No
Preschool	3	8	3 yrs.8mth.	5	6
Primary	3	25	8 yrs 3 mth.	13	15
Adolescent	0	10	13 yrs 4 mth.	5	5
Adult	1	2	18 yrs 0 mth.	1	2

*In years. Mean age of total sample was 13 years 4 months.

7.2.3 Area Category

Approximately two thirds of the sample lived in the urban area, while the remainder came from rural Kuwait. As indicated in Chapter Four, there are currently few specialised facilities for family members with autism in Kuwait, which means autistic family

members may have to be taken some distance from their homes to receive education and other help appropriate to their condition. Families living in rural areas may have particular difficulty coping with an autistic family member, because of their relatively greater isolation.

7.2.4 Number of Siblings

It has been suggested in Chapter Three that the presence of an autistic child in the family poses particular problems for siblings, and some writers (Attwood, 1998; Happé, 1994; Schopler, 1995; Wing, 1996) have suggested that the strain on the family of an autistic child may be related to the age of siblings. The data on number of children (besides the autistic child) in the family is shown in Table 7.3.

Table 7.3 Number of Siblings (N = 52).

No. of Siblings	Frequency	%
0	2	3.9
1	6	11.5
2	14	26.9
3	13	25.0
4	9	17.3
5	6	11.5
More than 5	2	3.9
Total:	52	100.0

As the table shows, only two of the children surveyed were *only* children. Over half had two or three siblings and a third had four or more. Thus, for most families, the strain of coping with an autistic child may be compounded by that child's relationships with siblings, and the difficulty for parents of balancing the competing claims for attention of all their offspring. Further research needs to be conducted to ascertain the perceptions of siblings in Kuwait, related to stress they experience.

7.2.5 Age of Siblings

Table 7.4 Age of Siblings

Age	Frequency	%
0-2	15	28.8
3-4	16	30.8
5-7	28	53.9
8-11	30	57.7
12-16	25	48.1
17-18	6	11.5
19-21	5	9.6
21+	4	7.7

(Multiple response, consequently, percentages total more than 100)

It can be seen that a small number of families had offspring who had reached adulthood and might be able to provide help and support in caring for the autistic family member. In more than half of cases, however, parents had one or more babies or pre-school children to cope with in addition to the autistic child. Moreover, almost half the children surveyed had adolescent siblings in the 12-16 years age range. In these families a typical problem might be siblings' embarrassment about the odd behaviour of the autistic family member (Wing, 1996; Aarons and Gittens, 1999).

7.2.6 Child Disorder

The distribution of the sample by the disorder with which they had been diagnosed is shown in Table 7.5.

Table 7.5 Child Disorder

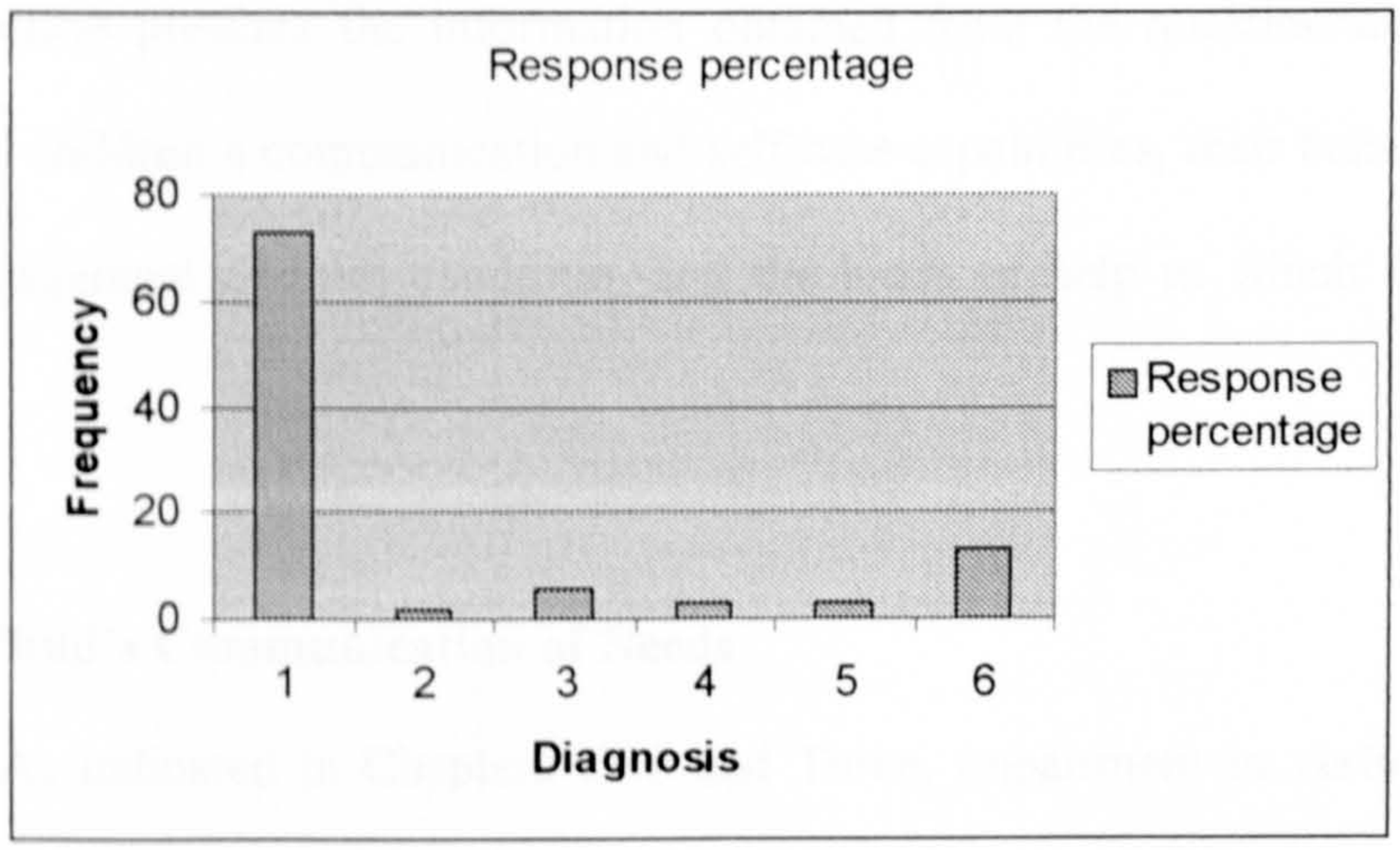
Disorder	No.	%
Autism	38	73
Developmental delay	1	1.9
Emotional disability	3	5.8
Mental retardation and no autism	3	5.8
Mental retardation and autism	7	13.5
Total:	52	100

As the table shows, almost three-quarters of the surveyed children had been diagnosed as having autism, while a further 13.5% were said to have autism plus mental retardation. Thus, 13.5% of the sample, in total, had diagnoses other than autism.

The above data was accessed from medical professionals in Kuwait, and from some of the records held by the schools where the cohort were attending, and from clinics. The measure to ascertain whether these children were autistic was by use of the DSM-IV. Because of the fact highlighted in the review of literature that some very able children can also have autism, there is a likelihood of misdiagnosis, but for the purposes of this initial study it was necessary to accept the professional decisions, as the researcher is not medically trained. Conversely, some children which the researcher saw appeared to display attributes of autism but they had not been officially diagnosed as such, therefore, it was not possible to include them in this study. This dilemma of problems with diagnosis is perceived by the researcher as a future research area.

The following is a graphical representation of the data in the above table.

Figure 7.1 Frequency percentage of diagnosis.



Legend - 1 = Autism; 2 = Developmental delay; 3 = Emotional disability; 4 = Mental retardation; 5 = Mental retardation and no autism; 6 = Mental retardation and autism.

7.2.7 Medication

Twenty-eight (54%) of the sample were not taking any medication. Of those prescribed medications, 12 were taking a single drug, commonly known as Mellerill. 12 were taking two or three drugs in combination (Nuthera and DMG for example) and one child was taking a combination of four drugs. The most commonly prescribed drugs were Nuthera, DMG and Mellerill, each of which was taken by 6 children, and Debakine, taken by 4 of the sample. Two children were taking vitamins/minerals, either alone or in addition to prescription drugs.

As stated in the review of literature, the above drugs are the most commonly prescribed in the western world; hence they are used by medical professionals in Kuwait.

7.3 Analysis of Questionnaire Data

This section presents the information obtained from the questionnaires regarding the sampled children's communication and self-care capabilities, their behavioural problems, the management of their condition, and the kinds of help to which families have had access.

7.3.1. Child's Communication of Needs

As indicated in Chapters Two and Three, impairment in verbal and non-verbal communication is characteristic of autism and indeed, is one of the defining criteria of DSM-1V (American Diagnostic and Statistic Manual 4th Edition). All but two

respondents indicated that their child had at least one way of communicating his or her needs. The relevant data are shown in Table 7.6.

Table 7.6 Child's Communication of Needs

Method	No.	%
Hand only	15	30
Speech only	8	16
Crying	3	6
Leading Carer	2	4
Multiple methods	22	44

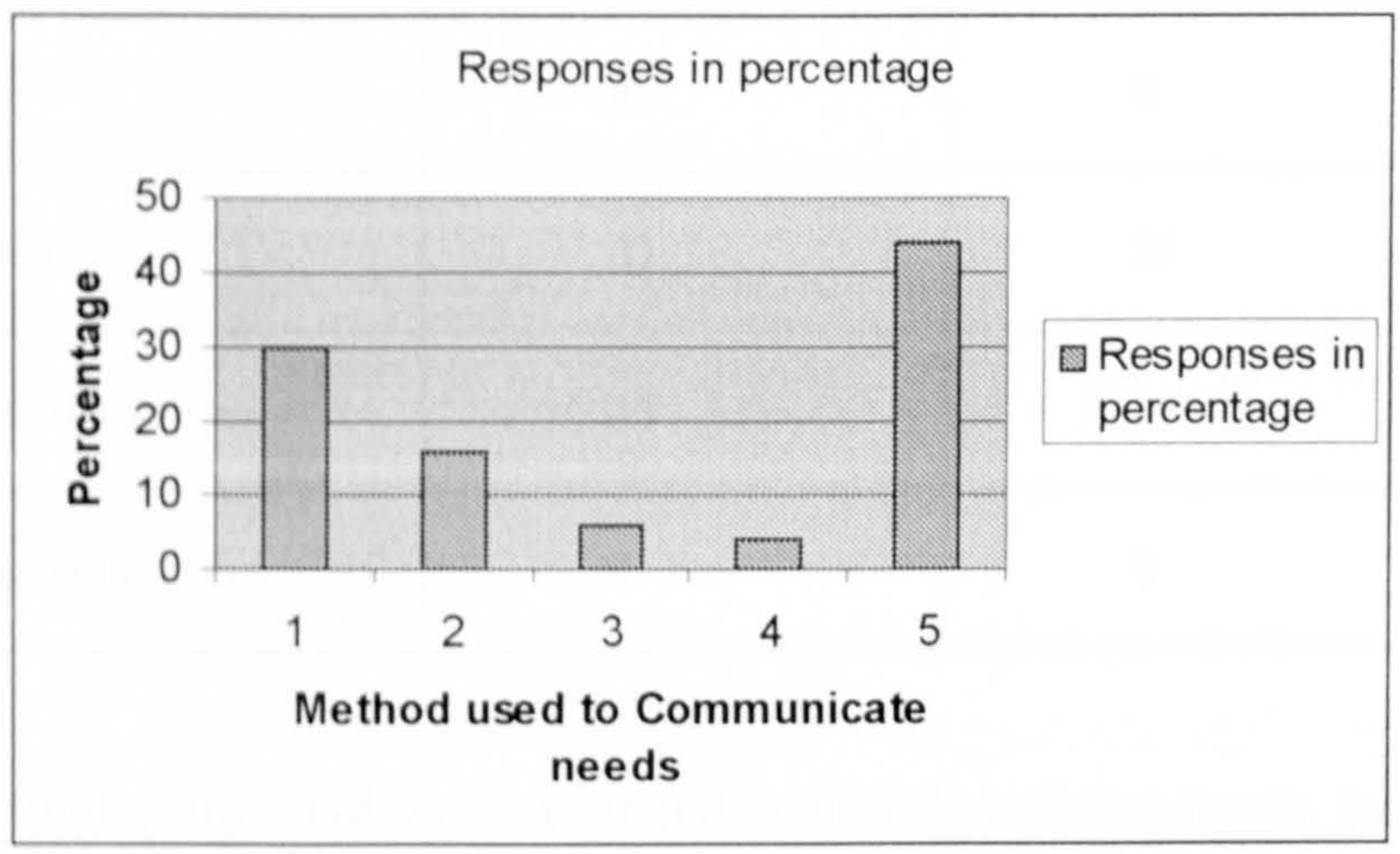
N = 50 Missing responses = 2

The most commonly used method of communicating need was by hand signals. Not only did nearly a third of the sample rely on this method alone, but almost all those who used multiple methods used hand signals as one of them; often the dominant one. Although almost half the children were said to use speech, only 8 relied on it completely. Moreover, it should be noted that several respondents qualified this answer, saying that the child used "simple" speech or "sometimes says one word", or "cannot use complete, correct sentences". Four of the "multiple methods" users were said to help themselves to

what they wanted, e.g. to take food from the refrigerator; if they could not manage by themselves, they would communicate their needs by shouting, gesturing, or leading the carer to what was needed; only one of these four children used speech.

The following is a graphical representation of the data in the above table.

Figure 7.2 Responses in Percentage to the Method used to Communicate Needs



Legend - 1 = Hand only; 2 = Speech only; 3 = Crying; 4 = Leading Carer; 5 = Multiple Methods

7.3.2 Ability to perform self-care skills.

Respondents were asked about their children's self-care skills, in terms of ability to dress/undress, eat, bathe and use the toilet without assistance. The responses are summarised in Table 7.7.

Table 7.7 Ability to Perform Self-Care Skills Unaided

Child can:	No.	%
Dress/undress	16	31
Eat	28	54
Bath	4	8
Use toilet	13	25
Do all of the above.	15	29
Do none of the above.	4	8

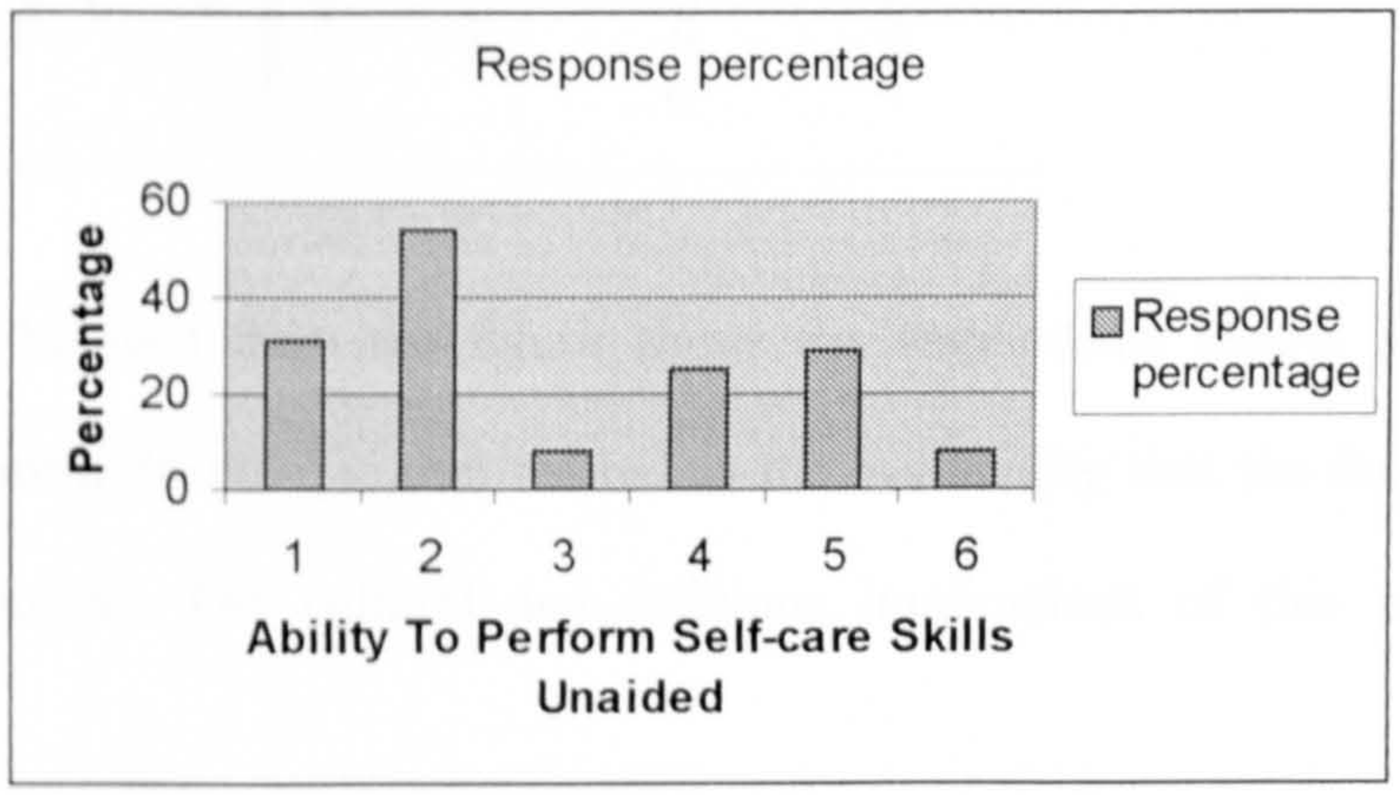
Fewer than a third of the children could attend to all their self-care needs, but most could perform one or two tasks unaided, and others with a little help.

As the table shows, eating was the task which was most frequently performed unaided; more than half the sample could do this. Bathing was the skill least frequently performed unaided, though several children were said to be able to do it with help. Interestingly, one mother of a seven-year old boy indicated that she helped with this task because she wanted to, rather than because the child really needed help, which raises the question whether some children who were regularly helped with certain tasks might be capable, with teaching and encouragement, of doing more for themselves.

Generally, it was the older children (12+) who were capable of meeting all their self-care needs. A small number of children were said to have other capabilities, in addition to those shown in the table. Two could ride a bicycle, and two of the older boys (aged 10 and 14.5 years) could operate the video machine. The same two boys were said to be able to select goods in a shop, though only the 14 year old could handle small sums of money.

The following is a graphical representation of the data in the above table.

Figure 7.3 Responses in Percentage to Ability to Perform Self-Care Skills Unaided

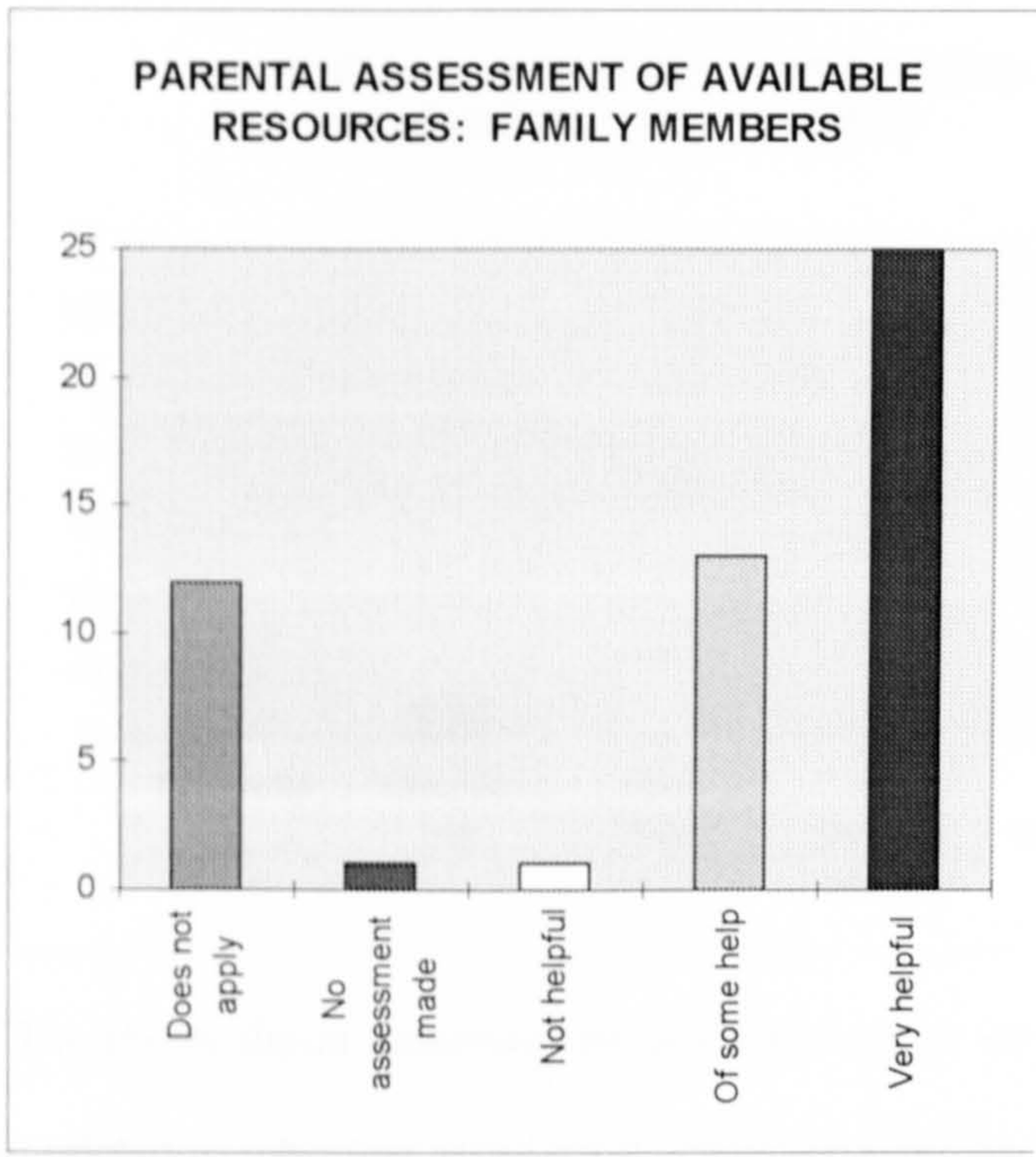


Legend - 1 = Dress/undress; 2 = Eat; 3 = Bath; 4 = Use toilet; 5 = Do all of the above; 6 = Do none of the above

7. 4 Parental Assessment of Available Resources

The following table and graph are self explanatory as the parental assessment is that family support is the most helpful resource available.

Figure 7.4 Parental Assessment of Available Resources by Categories

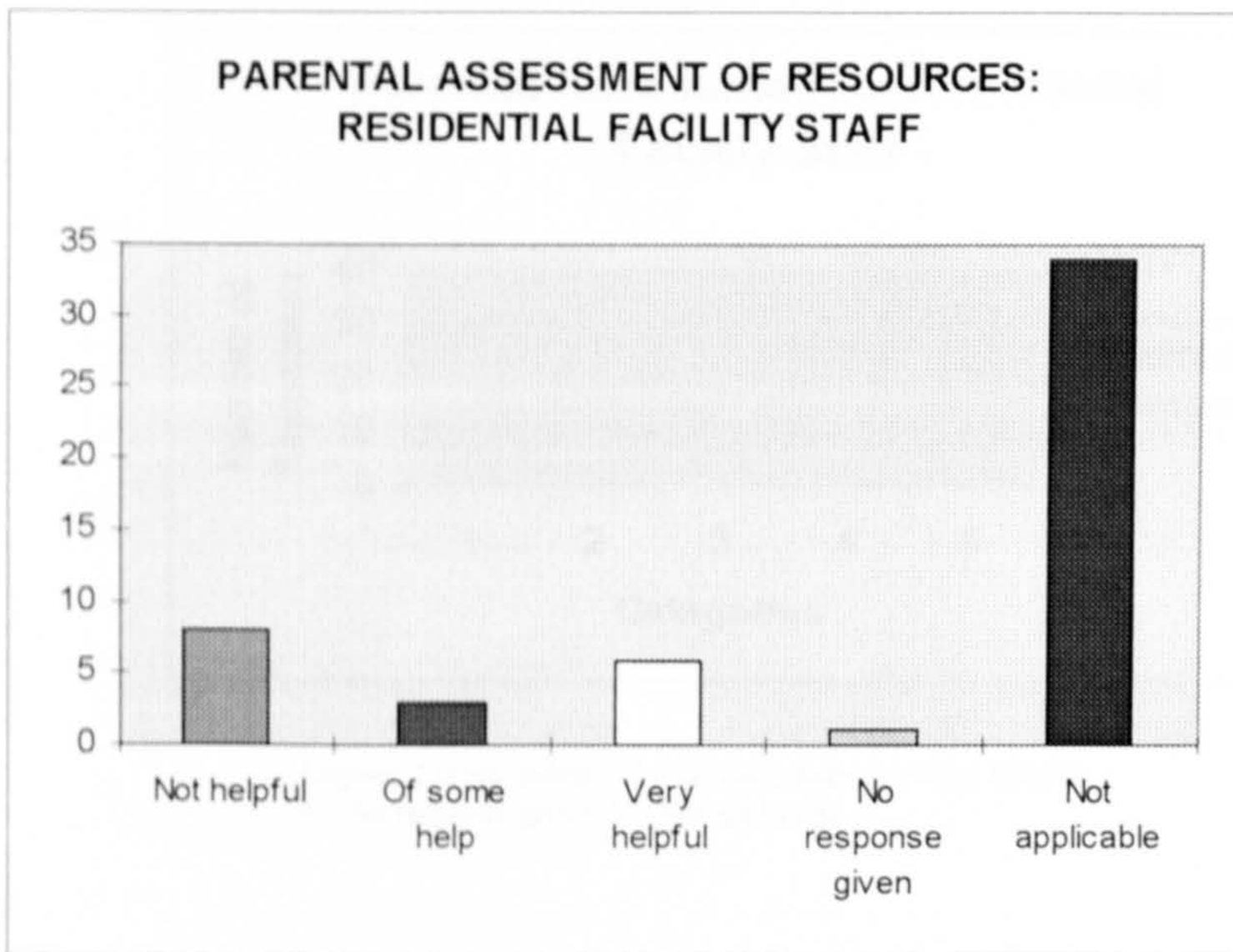


As can be seen from the figure above the respondents clearly gave a highly significant response to the question related to the availability that the family members give when required. The cultural and religious implications of this result will be discussed later.

7. 5 Parental Assessment of Residential Facility Staff

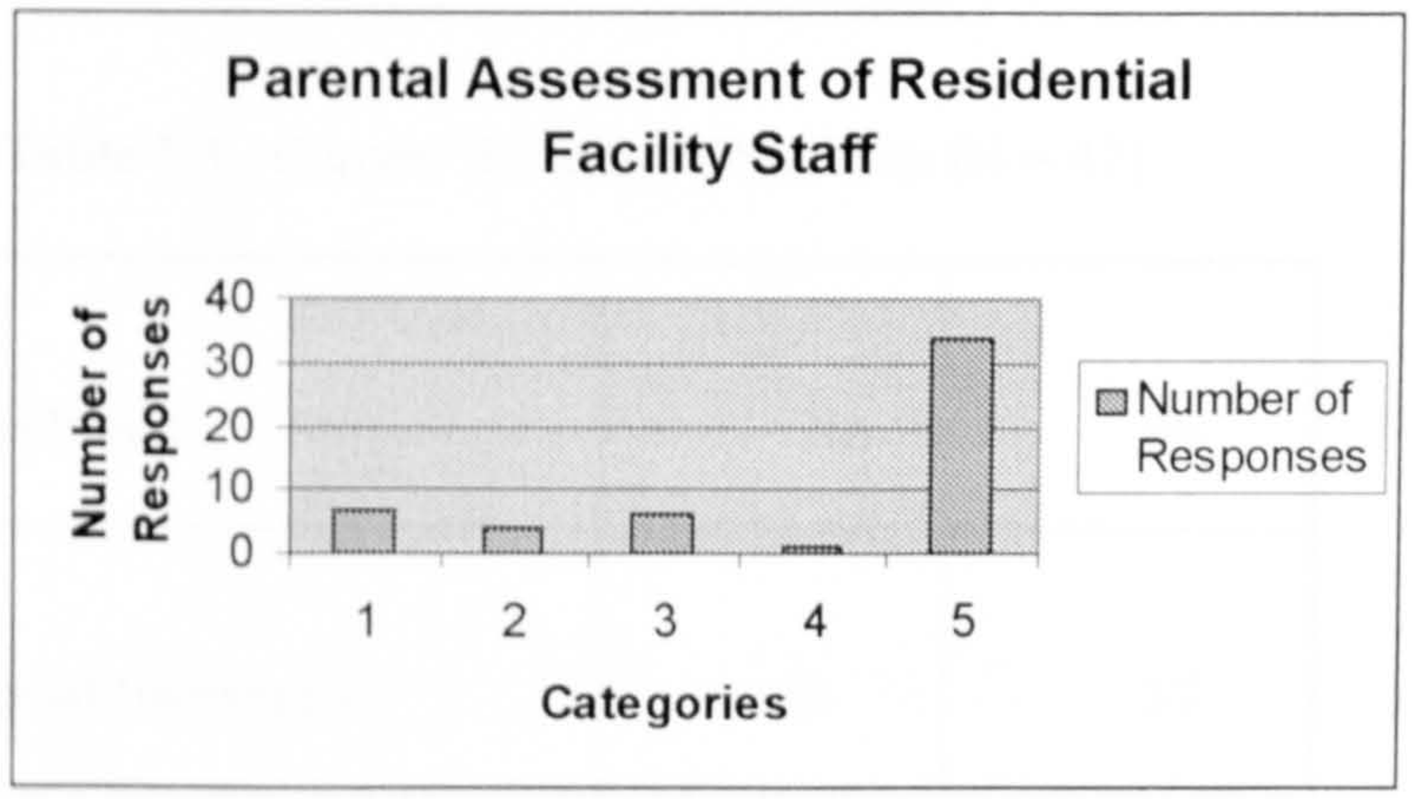
The following table and graph are self explanatory as they show a highly significant response to help from residential facility staff as being Not Applicable.

Figure 7.5 Parental Assessment of Resources: Residential Facility Staff.



The above figure demonstrates that there was a very significant response to the question related to resources provided by residential facility staff. Again, the cultural and religious implications of this result will be discussed in the next chapter. The following is a graphical representation of the data in the above figure.

Figure 7.6 Parental Assessment of Resources: Residential Facility Staff.



Legend: 1 = Not helpful; 2 = Of some help; 3 = Very helpful; 4 = No response given; 5 = Not applicable.

These results will be discussed more fully in the next chapter, because the cultural traditions in Kuwait are for the family member to remain within the family, as opposed to western culture where there are more choices, e.g. local residential facilities, available.

7.6 Current Behaviour Problems

When asked about children's behaviour problems, three parents gave no response, and a further two indicated that there were no problems. There were also some who interpreted "behaviour problems" in terms of the self-care skills considered above; for example six referred to problems with toileting. A number of common themes emerged, however. These are shown in Table 7.8 below.

As the table shows, the most frequently mentioned problems were difficulties with communication/speech, anger and aggression and imperviousness to danger. The

latter was manifested in such actions as running into the road, climbing onto the roof, picking up sharp objects and playing with electrical wires.

Table 7.8 Current Behaviour Problems (N = 47)

Problem:	No.	%
Social (isolation)	8	17
Communication/speech	12	26
Obsessiveness/inflexibility	8	17
Self Injurying Behaviour	6	13
No sense of danger	10	21
Anger/temper/aggression	12	26
Destructiveness	5	11
Hyperactivity	5	11

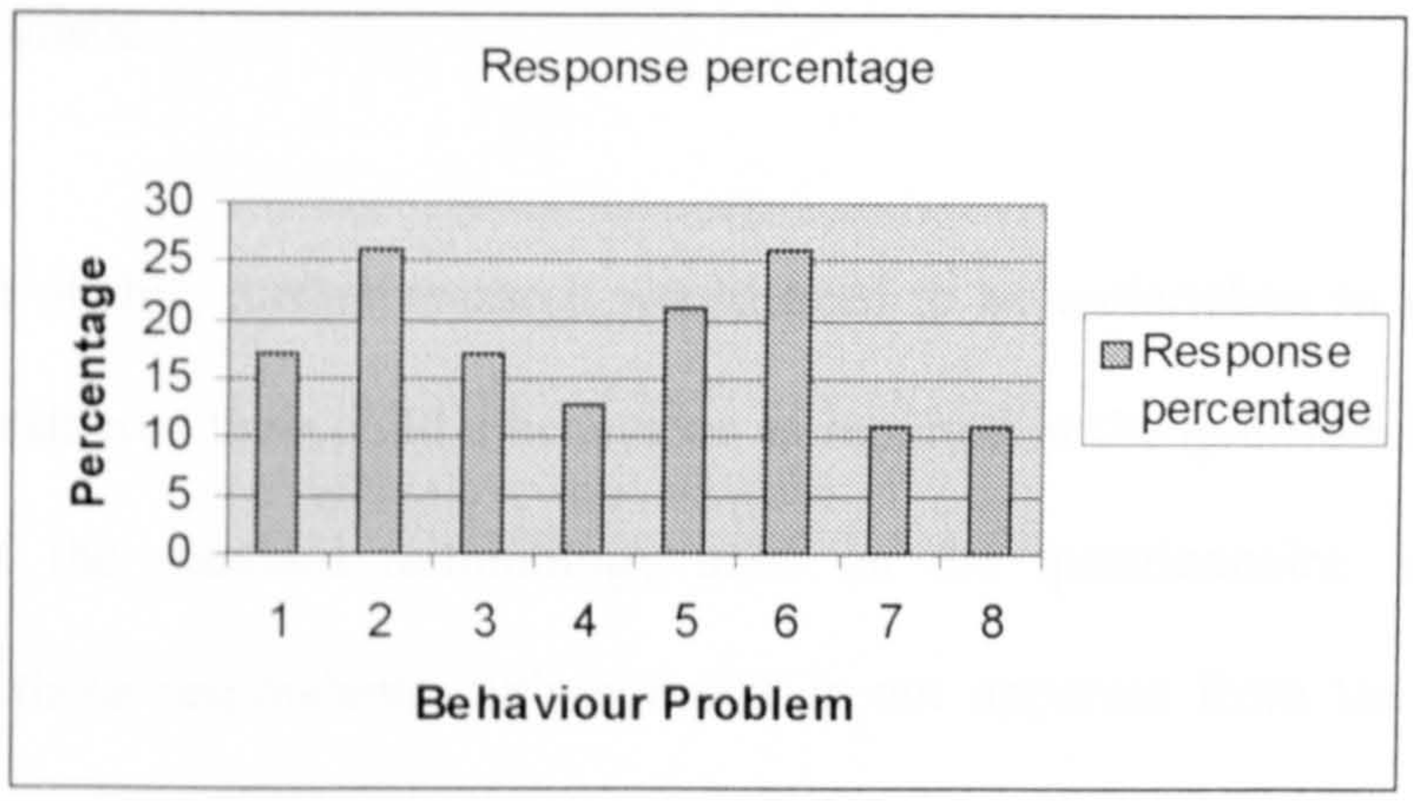
Several parents reported problems in the area of social interaction with other children, and wishing to be alone. Those who reported obsessiveness in their children gave such examples as refusing new clothes, demanding the same foods, repetitive play behaviour and refusal to be distracted from wants.

Six children were said to engage in self-injurious behaviour, such as head banging and hitting or biting themselves, while five were destructive of property and a similar number were hyperactive. These claims were confirmed by observation from the researcher whilst establishing relationships with the parents and families of the sample.

These results support the findings of research detailed in the Chapters above detailing the impact of autistic children on their families and the review of literature. For example, Schreibman (1988) describes the most dramatic behavioural abnormality manifested by autistic children as self-injurious behaviour (SIB). Similarly, Aarons and Gittens (1999) noted that one of the numerous features of observable behaviour of children with autism can often be displays of flattened, excessive or inappropriate effect, along with displays of irrational fears related to the demand for sameness, or the display of lack of fear.

The following is a graphical representation of the data in the above table.

Figure 7.7 Current Behaviour Problems (N=47)



Legend - 1 = Social (isolation); 2 = Communication/speech; 3 = Obsessiveness/inflexibility; 4 = SIB; 5 = No sense of danger; 6 = Anger/temper/aggression; 7 = Destructiveness; 8 = Hyperactivity.

7.6.1 Quantitative analysis of behaviours

Before detailing the results of each aspect of identified behaviour in the questionnaire it is important to state that the respondents were asked to indicate a measure of frequency of eight typical autistic behaviours in their child.

Analysis of the dataset shows that ten of the respondents, i.e. 20% of the cohort, listed all eight behaviours as occurring "not at all". A further five respondents listed only one of the eight behaviours as occurring – and this was listed as "infrequently". (see Figure 7.8 and Table 7.9). Thus, 28% of the survey's cohort could be said not to appear as autistic although all the children were diagnosed using the criteria from DSM-IV. Because of this highly significant skew, the researcher double checked with the various medical teams that scientific diagnostic tests had in fact been carried out on these

particular children. In each case standard testing procedures had been done. Each child was clinically diagnosed as 'autistic', therefore, the researcher has to accept that these children were autistic..

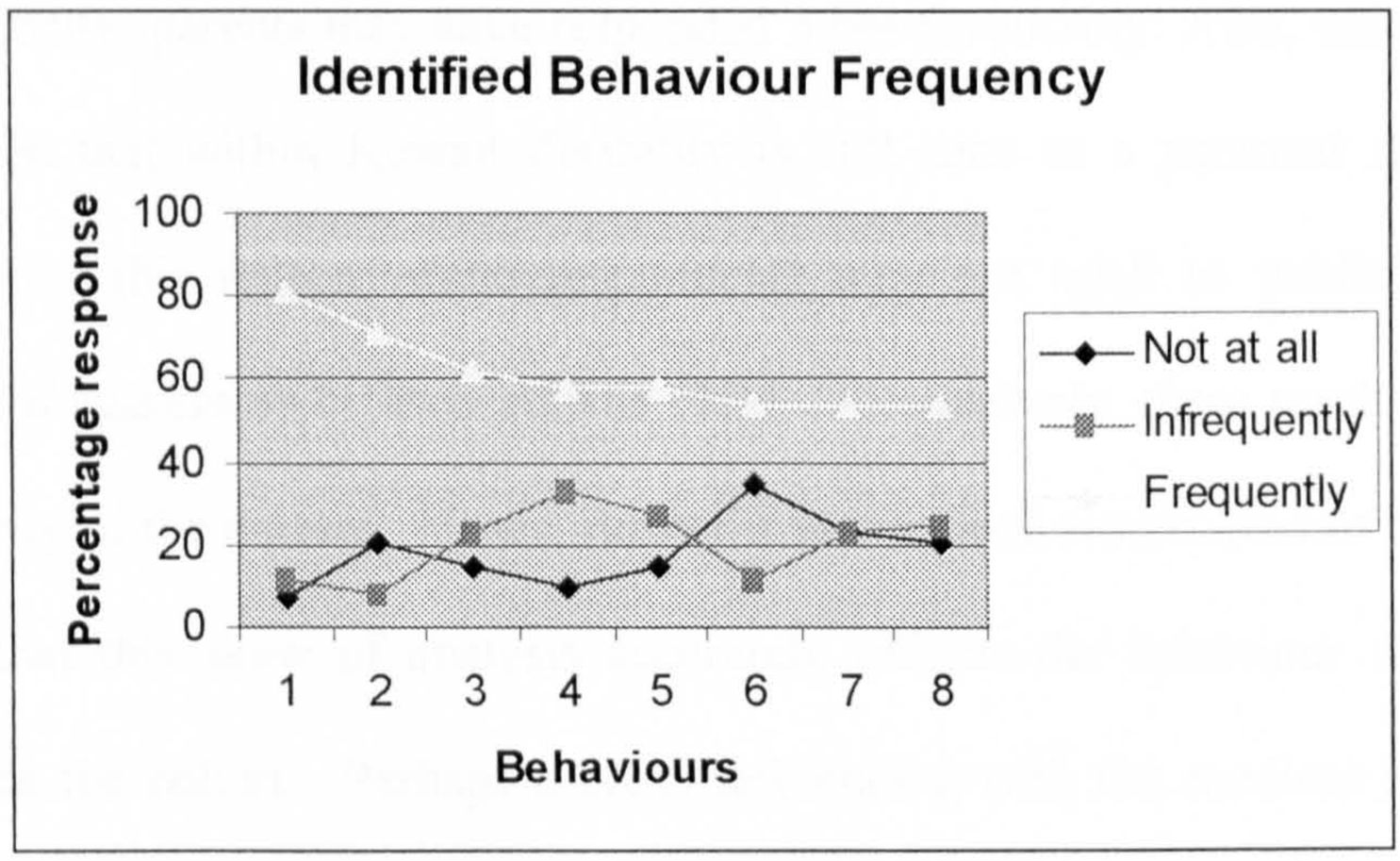
Because of this, further research would need to be undertaken to ascertain why respondents considered their child's behaviour as reported in the questionnaire. It could be simply that the standard terminology used on the questionnaire was not fully understood by these respondents, although this is not apparent from the audio tapes. Numerous alternative explanations are offered below. Each would require further investigation before conclusive conclusions could be drawn from this dataset.

Table 7.9 : A table of Analysis of Behaviours by identified type.

Behaviour Type	Number of responses	Overall Percentage Of Cohort
Aggression		
Frequently	4	7.7
Infrequently	6	11.5
Not at all	42	80.8
Self Injury		
Frequently	11	21
Infrequently	4	8
Not at all	37	71
Pica		
Frequently	8	15
Infrequently	12	23
Not at all	32	62
Destruction of Property		
Frequently	5	9.6
Infrequently	17	32.7
Not at all	30	57.7
Tantrums		
Frequently	8	15
Infrequently	14	27
Not at all	30	58
Stereotypic And Self Stimulating		
Frequently	18	34.7
Infrequently	6	11.5
Not at all	28	53.8
Withdrawing Behaviour		
Frequently	12	23
Infrequently	12	23
Not at all	28	54
Messiness		
Frequently	11	21
Infrequently	13	25
Not at all	28	54

The following is a graphical representation of the data in the above table.

Figure 7.8 Behaviour Frequency in Percentage.



Legend - 1 = Aggression; 2 = Self Injury; 3 = Pica; 4 = Destruction of Property; 5 = Tantrums; 6 = Seterotypic and Self Stimulating; 7 = Withdrawal Behaviour; 8 = Messiness.

7.6.1.1 Aggression

From the data collected in this study related to parents' experience and perception of the autistic child's behaviour it is possible to state that out of the cohort, 80.8% showed no aggression. This is a highly significant result and is not in line with the evidence presented in the Review of Literature. Generally, one of the main characteristics of autism is displays of aggression.

The researcher can only offer the explanation that in the Moslem religion, family life has very strict adherence to certain behaviour patterns. As such behaviour patterns

are fundamental and almost so entrenched in Moslem culture, the environment in which autistic children in Kuwait are raised may have a profound effect on certain aspects of the condition. Without further extensive research it is not possible to state emphatically that this may be a cause of less aggression. Further, caution has to be exercised as culturally it is not acceptable to criticise family members publicly. Thus, unconsciously and/or unintentionally, parents may have responded more favourably. Also, consideration needs to be taken that within Kuwait disability is still seen as a personal reflection on the family. For this reason, some respondents may not wish to publicly acknowledge outbursts of aggression by their autistic child. Alternatively, these results may simply be a peculiarity of the dataset. Hence, further investigations would need to be undertaken to confirm that this skew of analysis accurately reflects the behaviour displayed by the children in the cohort. Perhaps a cross referencing with the medical team and school personnel to confirm that, indeed, the children in question do not display outbursts of aggression, would be necessary.

7.6.1.2 Self Injury

As can be seen from Figure 7.8 and Table 7.9 there was a wide variance between respondents. 71% stated that their child does not "self injury", whilst 21% say that this "frequently" happens. 8% stated that such behaviour is "infrequent". Again, further investigations need to be undertaken for the reasons cited above.

7.6.1.3 Pica

Whilst 62% of the respondents stated that this behaviour does not happen at all, 23% stated that it happens but "infrequently", with a further 15% of respondents stating that this behaviour happens "frequently".

7.6.1.4 Destruction of Property

Again, the majority of respondents (57.7%) stated that their child did not display "destruction of property" behaviour.

A further 32.7% acknowledged that their child did destroy toys and other property, but this was "infrequent". Only 9.6% of the sample stated that their child displayed destructive behaviour "frequently". Again, these responses do not confirm research results cited in the Review of Literature.

7.6.1.5 Tantrums

As with the previous identified behaviour displays above, in this cohort 58% of respondents stated their child never has a tantrum, whereas, 27% stated their child does but it is "infrequent" and 15% state their child has frequent tantrum behaviours. Over half of the children described in this survey do not display behaviours widely associated with autistic children.

7.6.1.6 Stereotypic or Self-Stimulating Behaviour

Again, there is a highly significant skew of responses towards the "not at all" i.e. 53.8%. Whilst this may well be an accurate statement, cross checks would need to be conducted to ascertain why this particular cohort has such a highly significant skew. 34.7% of the respondents acknowledged their child does display stereotypic or self stimulating behaviour "frequently", with only 11.5% stating it occurs, but "infrequently".

This result also brings into question whether the respondents have clearly understood the questionnaire, although every effort was made to ensure clarity. Most, if not all, autistic children are readily identified by their stereotypic behaviour prior and subsequently to official standardised scientific testing procedures, so it is surprising that 54% of this cohort were said to display such behaviour "not at all". This requires further investigations to be conducted (See below).

7.6.1.7 Withdrawing Behaviours

Again, although this is acknowledged to be a behaviour typical of autistic children, 54% of this survey's respondents stated this never happened with their autistic child. An equal balance of the rest of the cohort, i.e. 23% for each alternative, reported that this pattern of behaviour was "infrequent" or "frequent".

7.6.1.8 Messiness

A highly significant proportion of 54% of respondents stated that their autistic child was never messy or caused mess. In contrast, 21% agreed their autistic child was

"frequently" messy or caused a mess, with 25% agreeing but stating that such incidences of messiness were "infrequent".

7.6.1.9 General Statement

It is noted that when the respondents were asked to indicate a measure of frequency of eight typical autistic behaviours in their child, ten of the respondents, which is almost 20%, listed all eight behaviours as occurring 'not at all'. A further five respondents listed only one of the eight behaviours occurring, and this infrequently.

These results would seem to indicate that either the parents are in denial and do not wish to be seen to be disloyal to their autistic family member, or there may well be some confusion in regard to the diagnoses of some of the sample. It was noted by the researcher (although not a professional in the diagnosis of autism) when in contact with some of the autistic family members, that they did not appear to him to display what would be considered challenging behaviour typical of autism.

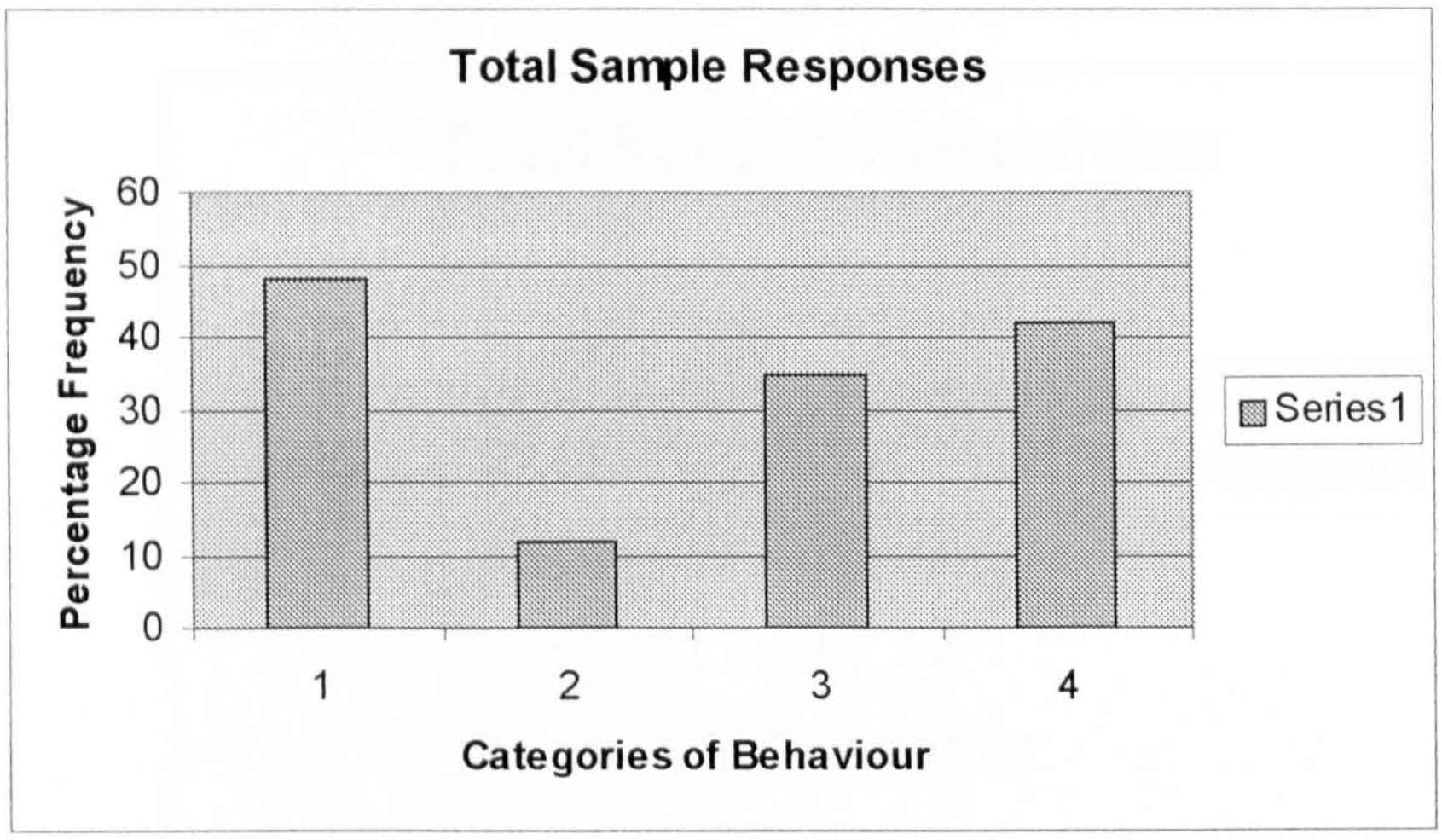
As there was a consistent nearly 54% of "not at all" responses in the last three categories of behaviour and 80.8%, 71%, 62%, 57.7% and 58% respectively for the first five categories, the researcher re-analysed the raw data to establish, if possible, whether these results were due to 53.8%-54% of the respondents simply putting "not at all" for each of the categories. It was found that this was not the case. Although a total of 54% or above was calculated, it was found that only 20% out of the cohort listed "not at all"

for all eight behaviours; the further 34% and above were accounted for by other respondents who did not fall within the identified 20% cited above.

Frequency of challenging behaviour was further assessed by grouping behaviours into four broad categories. Aggression towards others, self-injury, pica, and destruction of property (were grouped as destructive behaviour); yelling, screaming, and crying at a very intense level were grouped as tantrums. The other categories were stereotypical or self-stimulating behaviours, and withdrawing behaviours. Each area was answered on the same 3 point scale – frequently (once per day or more), infrequently (less than once per day), or not at all.

The following figures describe the findings related to the whole sample followed by a breakdown of the same information related to the four age group categories as opposed to analysing each attribute. This was felt to be necessary, simply to identify if there are similar results or if another trend emerges for the different age groups.

Figure 7.9 Percentage of Total Sample of parent respondents reporting frequency of Challenging Behaviour.

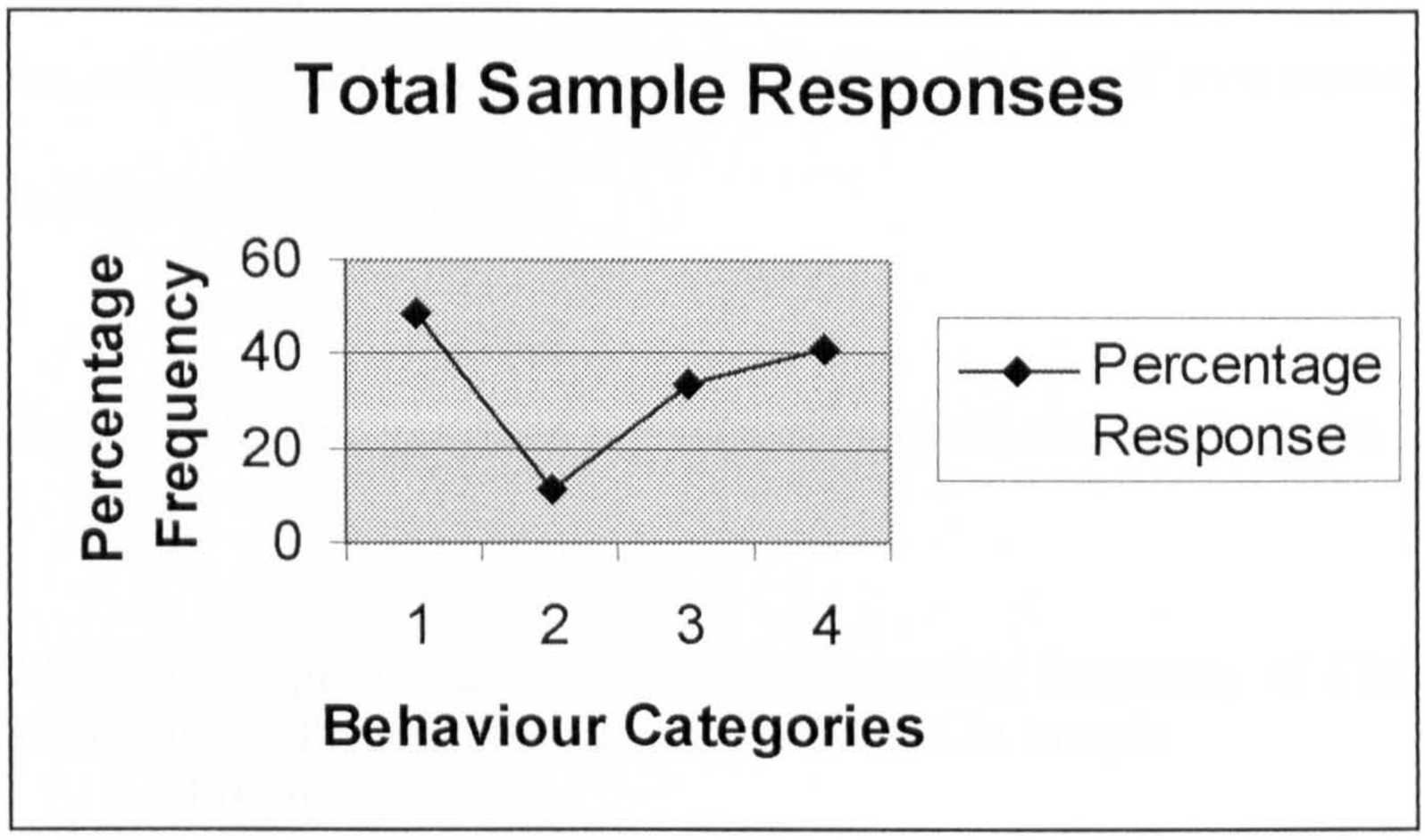


Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

From the above figure it can be seen that the most frequently displayed types of behaviour were destructive closely followed by tantrums and withdrawing type behaviours.

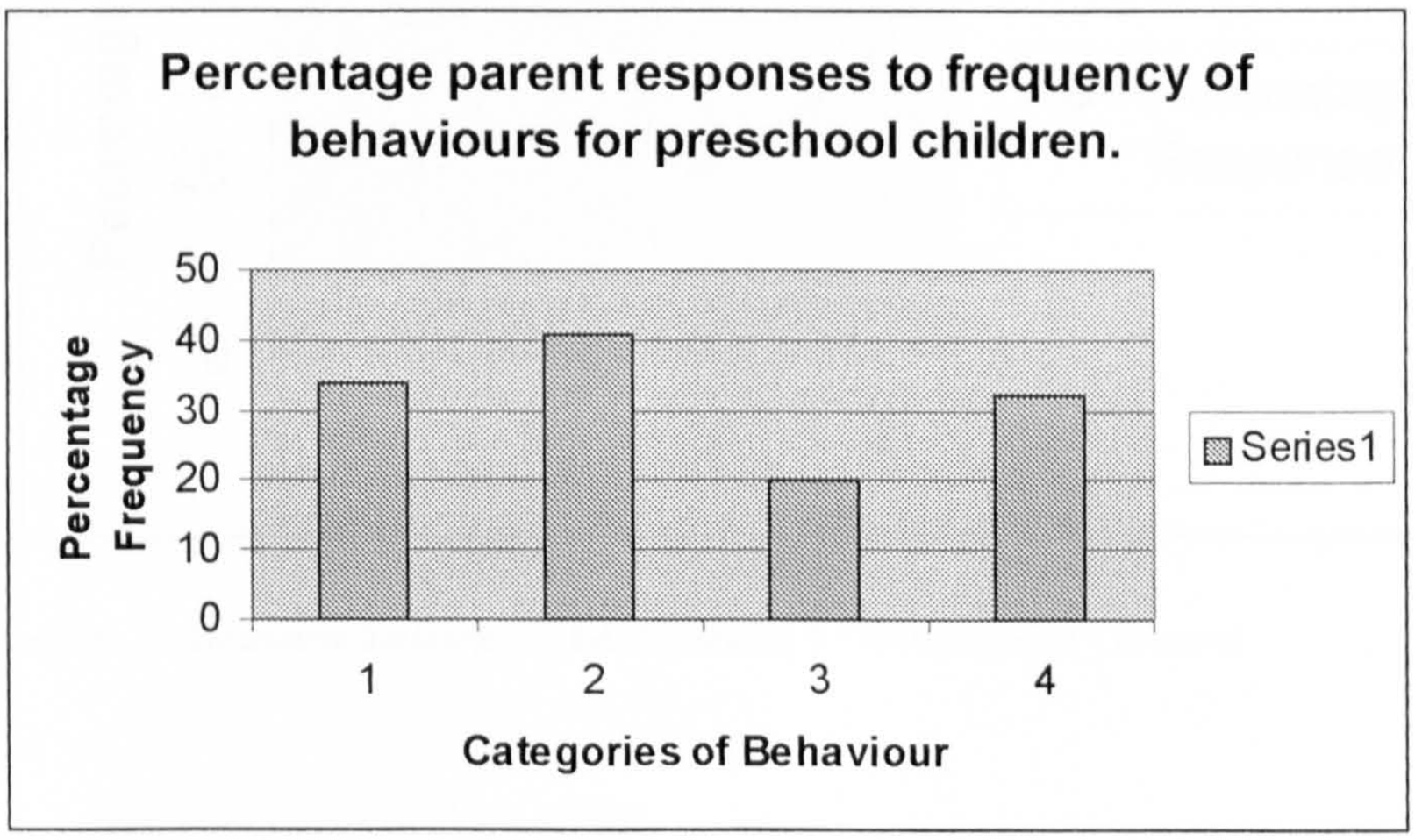
The following is a graphical representation of the data in the above figure.

Figure 7.10 Percentage of Total Sample of parent respondents reporting frequency of Challenging Behaviour.



Legend: 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums.

Figure 7.11 Percentage of parent respondents reporting frequency of Challenging Behaviour for Preschool aged autistic children in sample (Birth to 4 years).

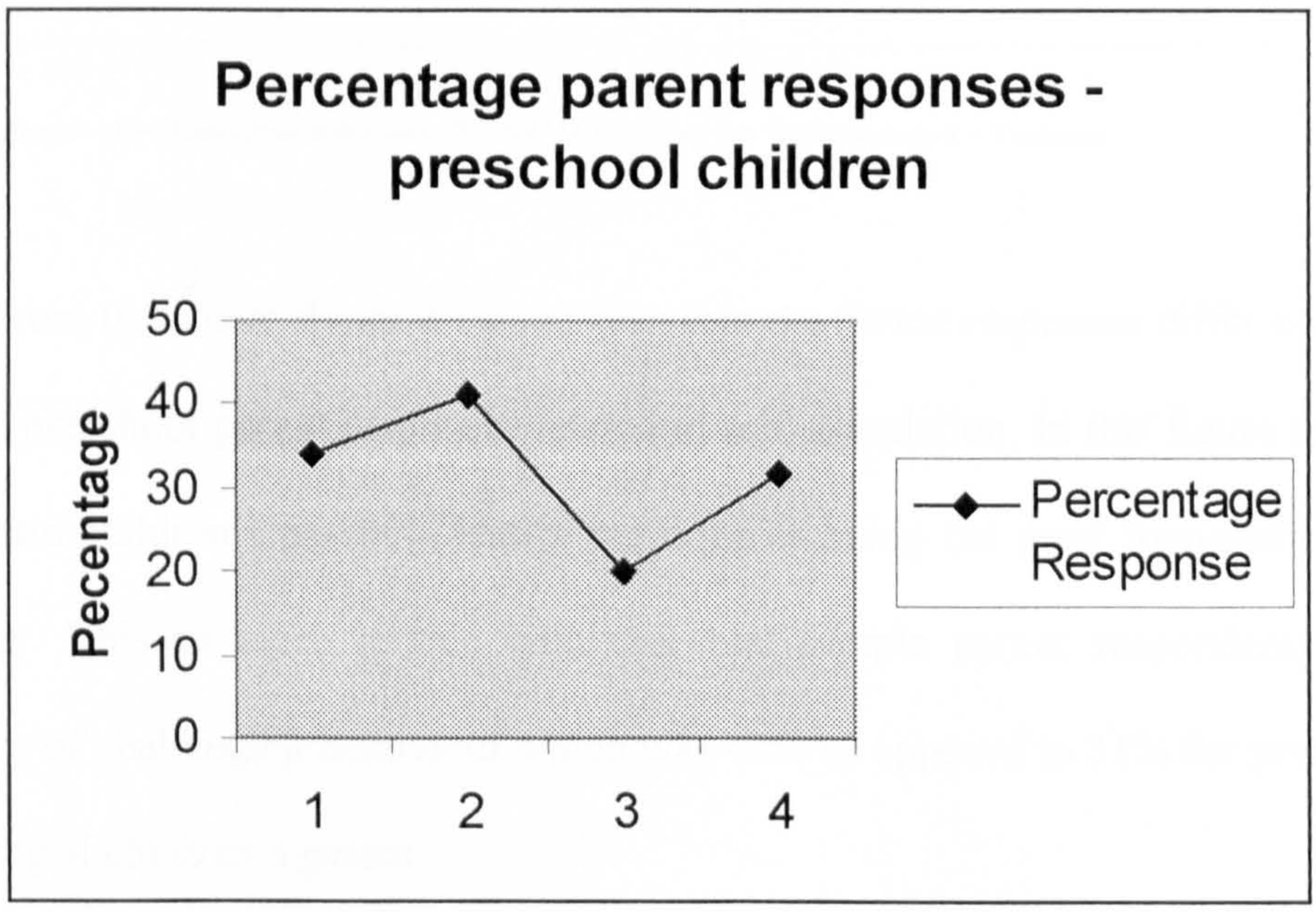


Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

The above figure shows that at the preschool age most parents responded that self stimulation was a highly significant category of behaviour, followed by destructive behaviour and tantrums being equal. This is different from the data collated in Figure 7.11 above, where the total sample response indicated that self stimulation was the least frequently demonstrated behaviour.

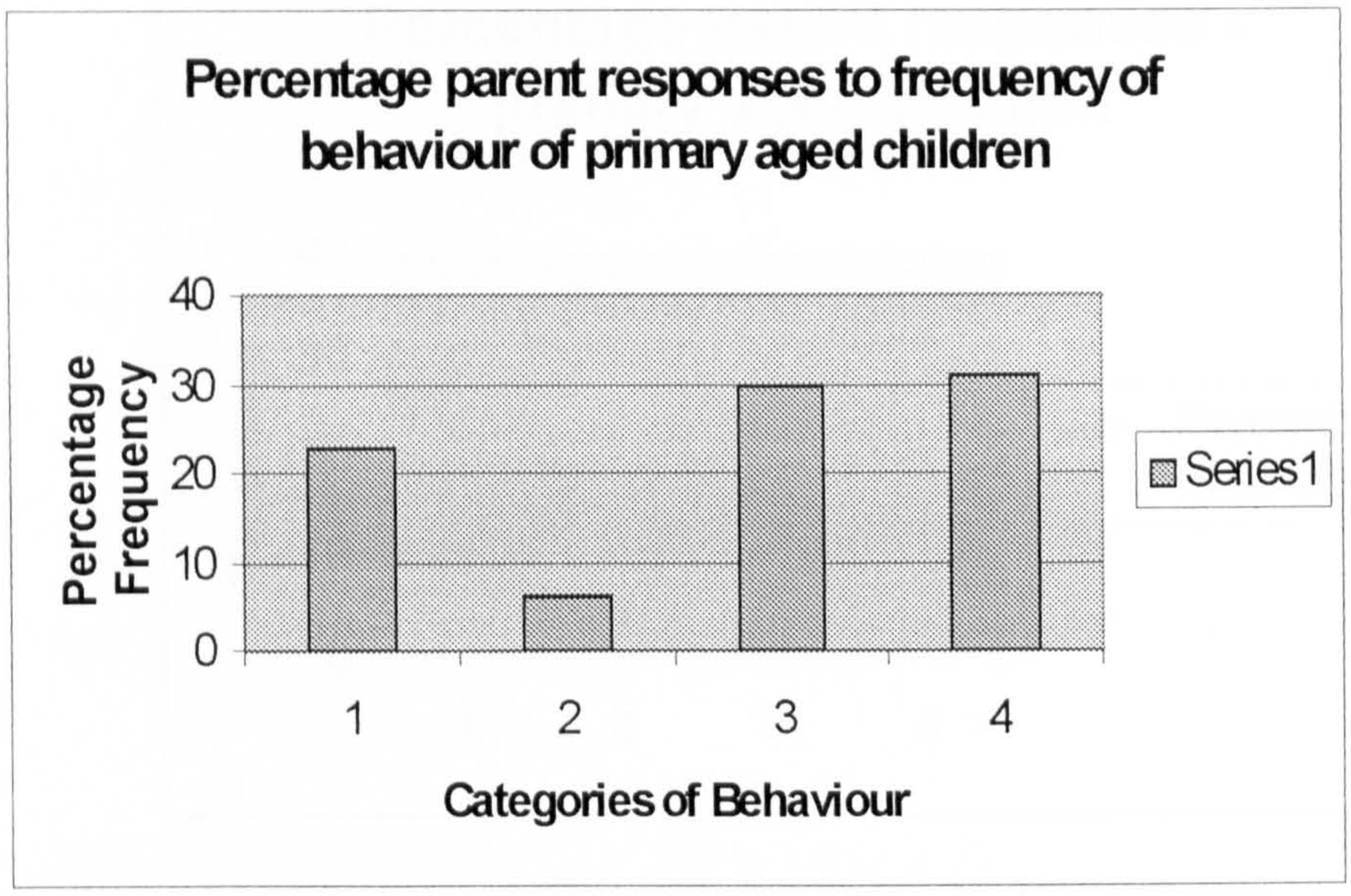
The following is a graphical representation of the data in the above figure.

Figure 7.12 Percentage of parent respondents reporting frequency of Challenging Behaviour for Preschool aged autistic children in sample (Birth to 4 years).



Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

Figure 7.13 Percentage of parent respondents reporting frequency of Challenging Behaviour for Primary aged autistic children in sample (7 – 11 years).

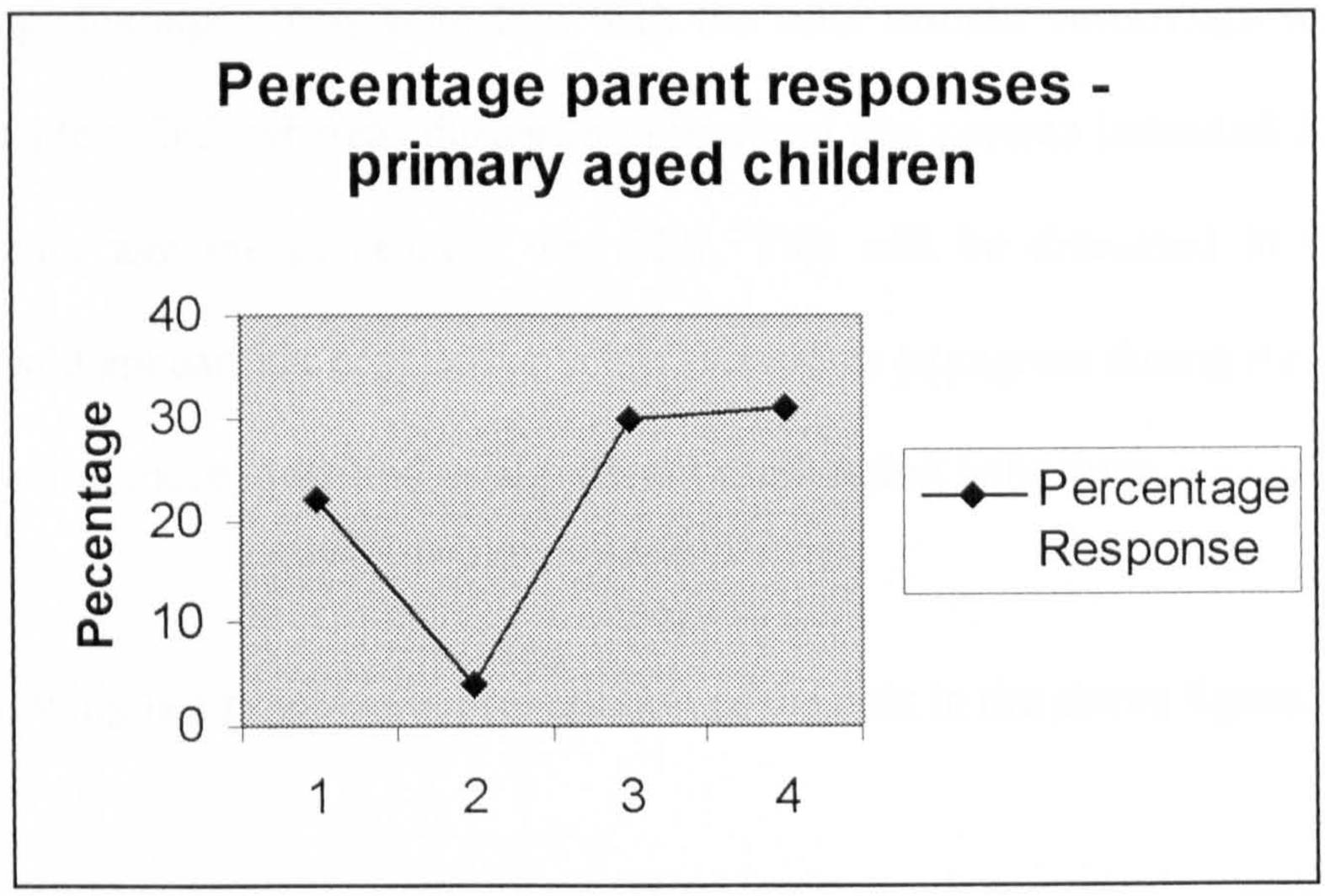


Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

From the above figure it can be seen that the parent responses differ considerably from the preschool parent responses related to self stimulation. In this figure the primary age autistic children's parents identify tantrums as being the most frequently displayed behaviour. This in more in line with the total sample parent respondents reporting frequency of challenging behaviour which was 42% as opposed to 31% for preschool and primary aged children's parent.

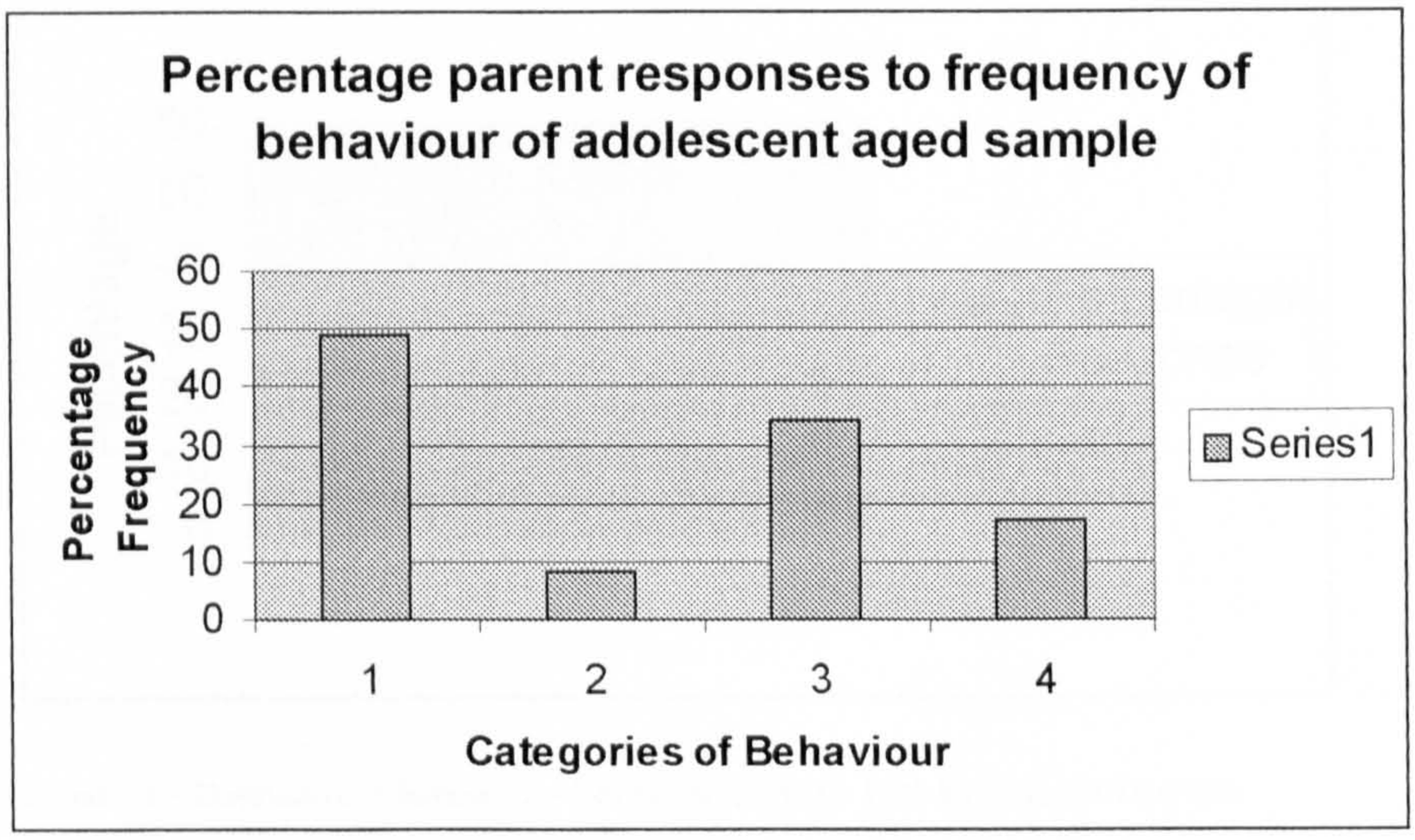
The following is a graphical representation of the data in the above figure.

Figure 7.14 Percentage of parent respondents reporting frequency of Challenging Behaviour for Primary aged autistic children in sample (7 – 11 years).



Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

Figure 7.15 Percentage of parent respondents reporting frequency of Challenging Behaviour for Adolescent aged autistic members in sample (12-17 years).

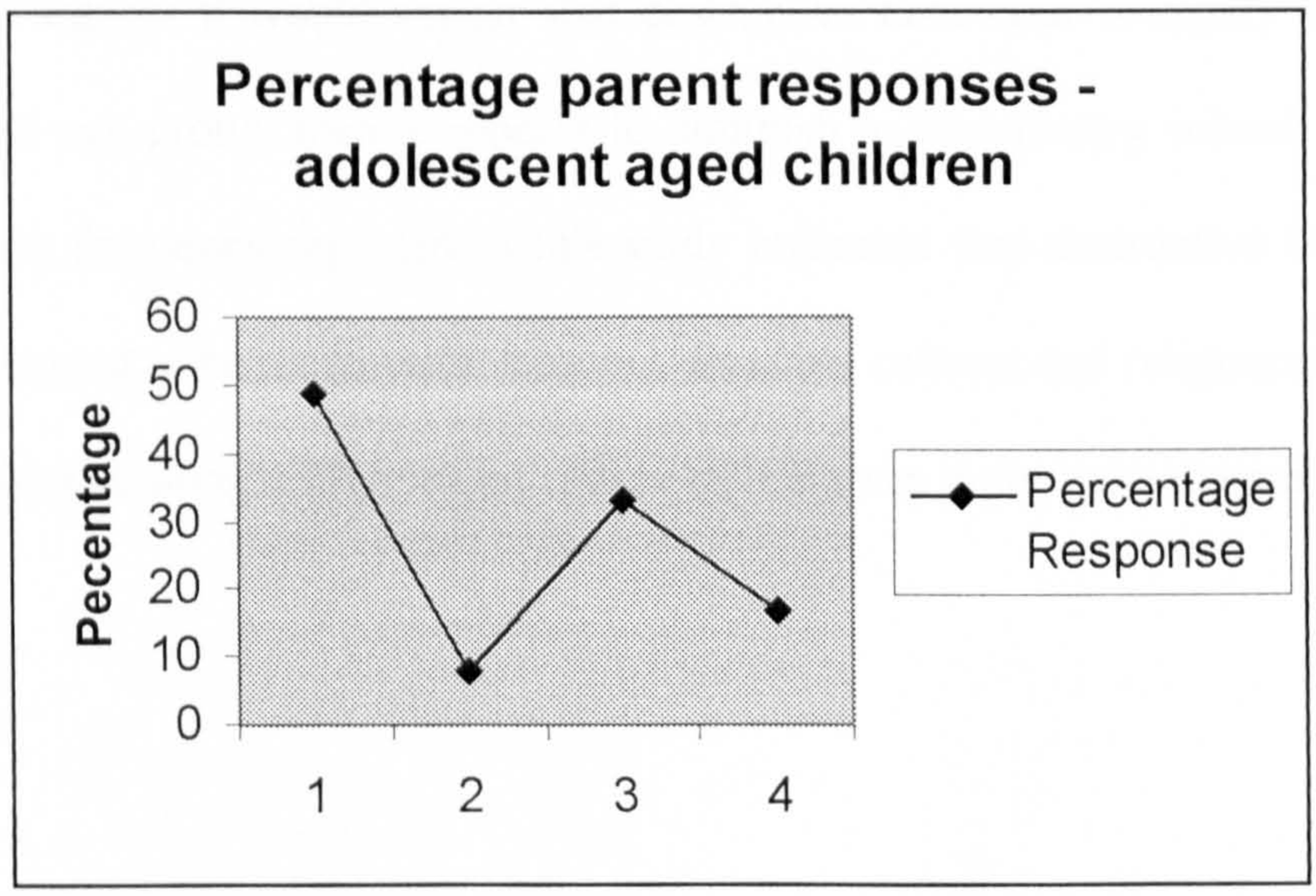


Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

From the above figure it can be seen that adolescent aged autistic members' parents identified destructive behaviour as the most significant and frequently displayed behaviour during this age. This is in line with the total sample percentage responses where 49% was identified, whereas during the preschool age parents indicated 32%, yet during the primary age the percentage was 22%. This will be discussed in the next chapter, as it would appear that destructive behaviour seems to regress during the primary age before becoming more identified as significant challenging behaviour.

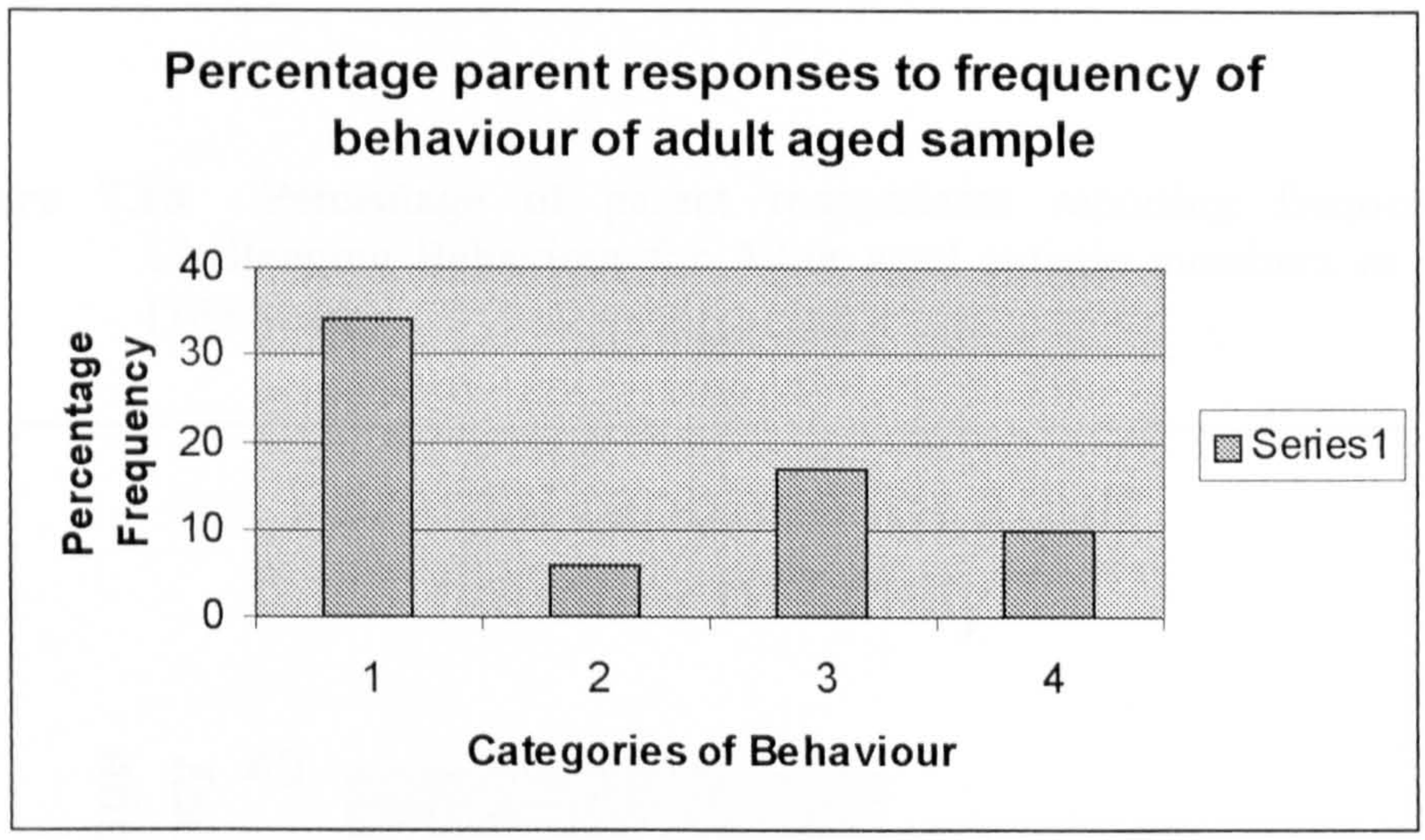
The following is a graphical representation of the data in the above figure.

Figure 7.16 Percentage of parent respondents reporting frequency of Challenging Behaviour for Adolescent aged autistic members in sample (12-17 years).



Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

Figure 7.17 Percentage of parent respondents reporting frequency of Challenging Behaviour for adult aged autistic members in sample (18+ years).

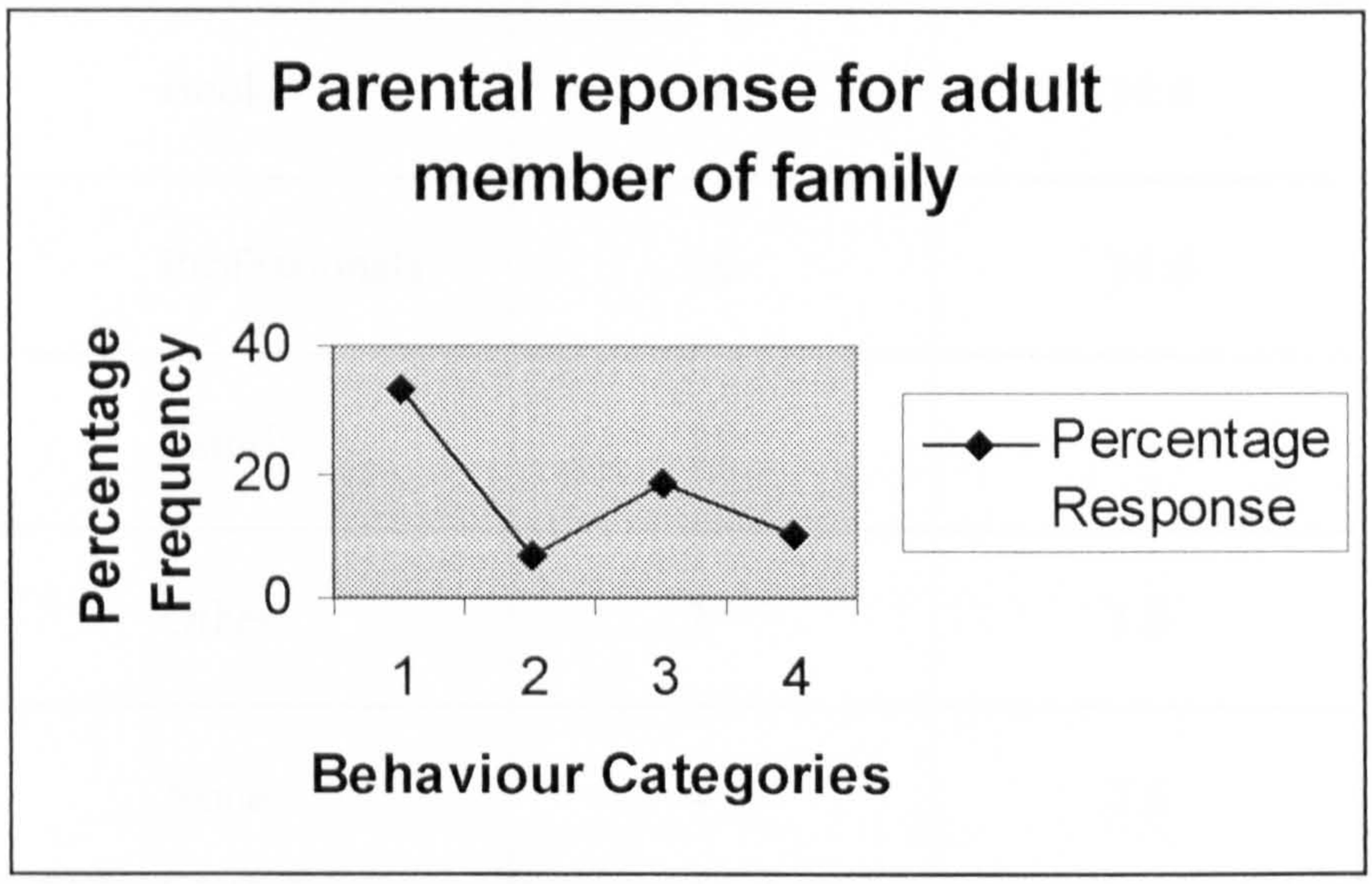


Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

From the above figure, the most frequently identified mode of behaviour cited by the parents was that of destructive behaviour. Again, interestingly following on from the previous figures it would appear that destructive behaviour is highly significant in the preschool age group, then it appears to diminish in the primary school age group. After which the frequency reported in this study indicated that destructive behaviour became and continued to be much more frequent. Possible cultural and religious explanations will be considered along with relevant review of literature in the next chapter.

The following is a graphical representation of the data in the above figure.

Figure 7.18 Percentage of parent respondents reporting frequency of Challenging Behaviour for Adult aged autistic members in sample (18+ years).



Legend - 1 = Destructive Behaviour; 2 = Self Stimulation; 3 = Withdrawing; 4 = Tantrums

7.6.1.10 Sources of Help with Child's Behaviour

Regarding the main sources of help and support to which parents had access in dealing with their child's problem behaviour in Kuwait, the data are as shown in Table 7.10.

Table 7.10 Sources of Help with Child's Behaviour

Source	No.	%
Teacher(s)/school	33	63.2
Books	18	34.6
Professionals	18	34.6
Family	25	48
Other	2	3.8
None	4	7.6

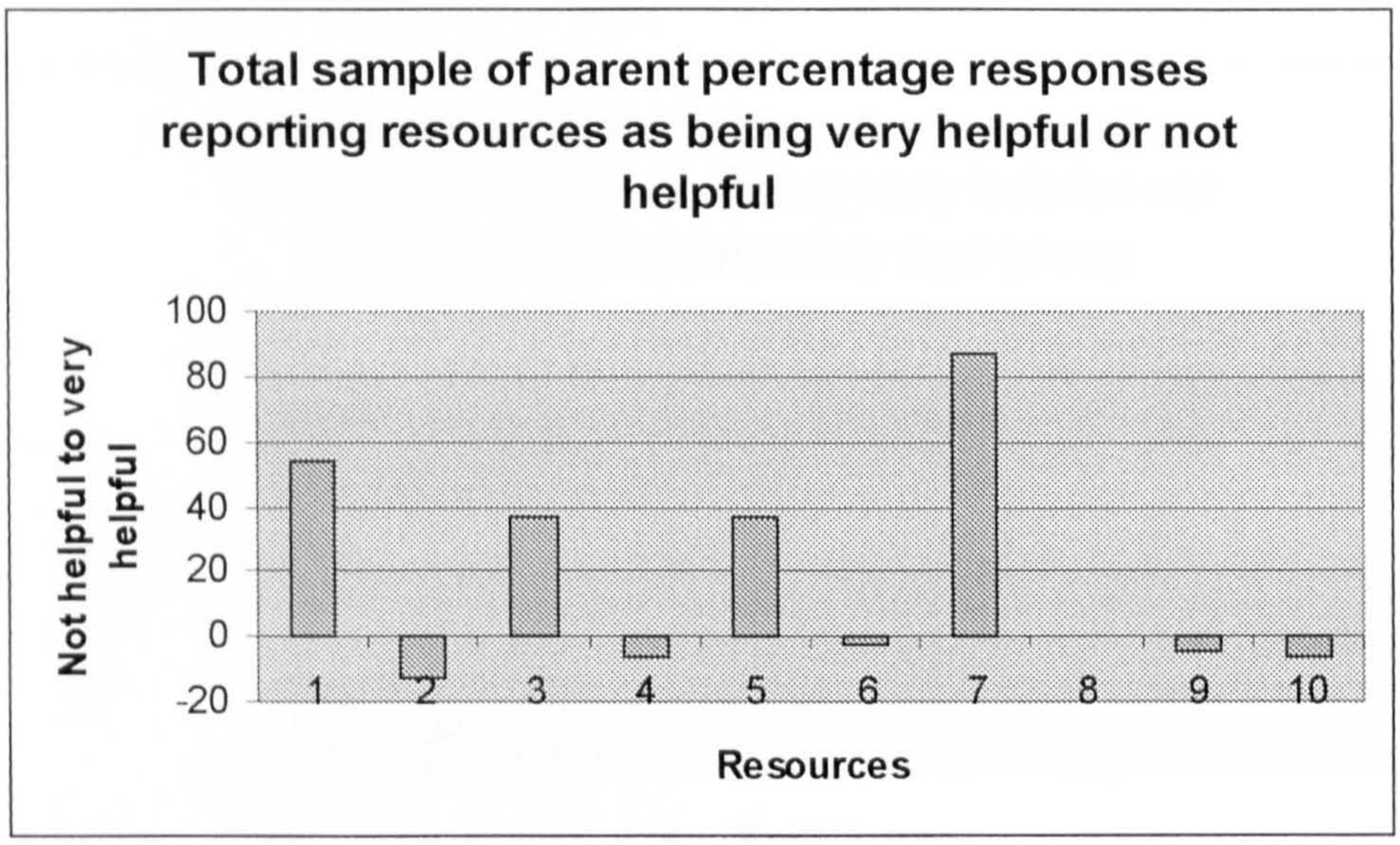
Note: Figures are multiple responses (several parents had more than one source of help. Therefore, percentages total more than 100.

As the table shows, the main source of help, used by nearly two-thirds of families, was the teacher. Next came the family, cited by almost half the sample. Books and professionals (doctor, psychologist, etc.) were each found to be good sources of help by a little over a third of respondents. Given the relatively widespread access to these four sources of support, it may seem surprising that five families indicated no support at all. All but one of these was from the urban area; in three cases, the diagnosis was mental retardation, with or without autism, while the other two were diagnosed autistic but not on any medication.

Further, parents were asked to indicate how helpful they had found various resources, such as teachers, books and other official publications, professionals (doctors, psychologists, social workers), families, others (to be identified by the respondent) or none of the above. These responses were then collated into the age groups preschool, elementary, adolescent and adult to calculate the percentage parent responses to the individual resources. Data are presented in Figures 7.19 to 7.23 on the perceived helpfulness of the resources, where 67% of the group indicated some degree of helpfulness.

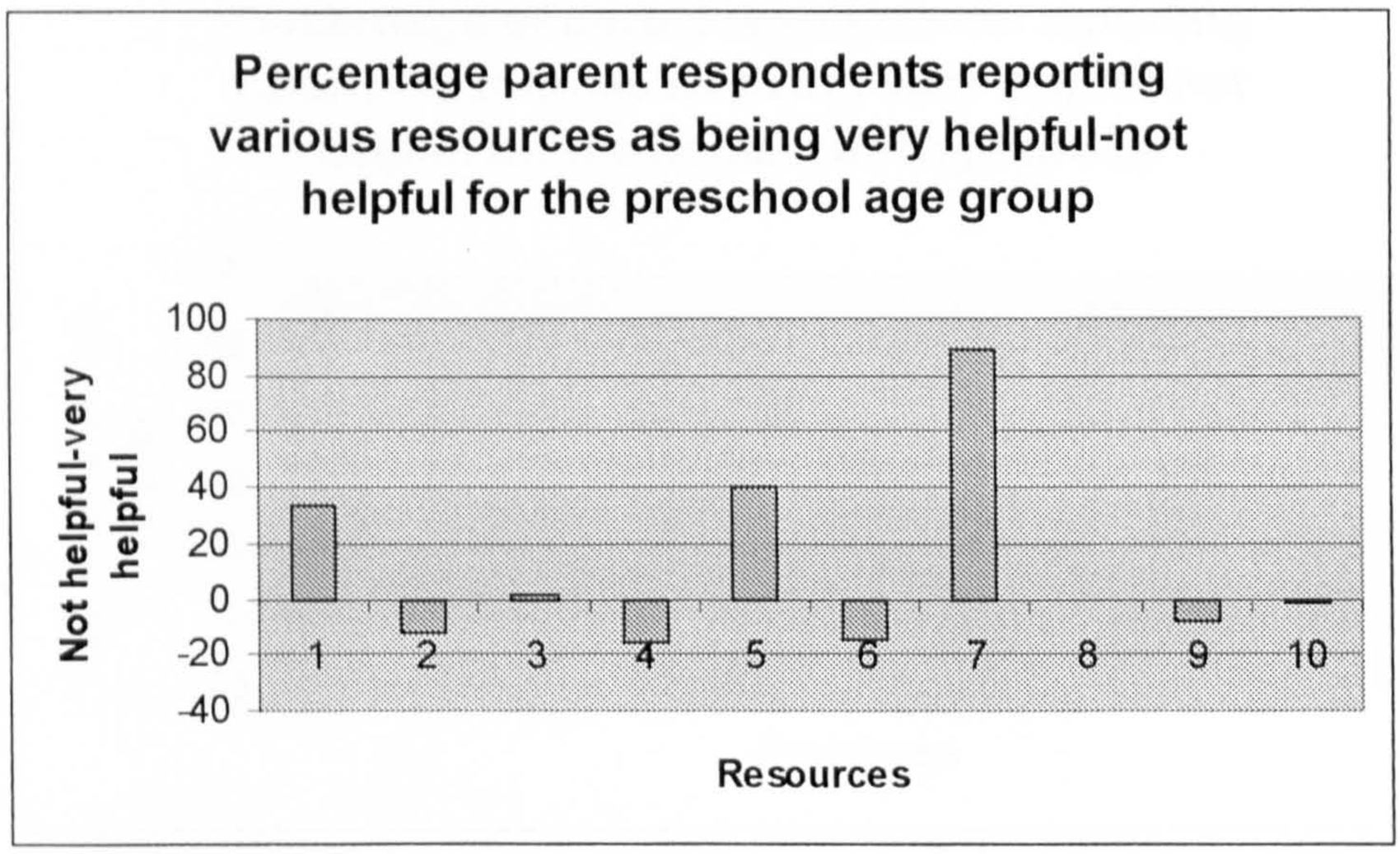
In the following figures the bars that extend above the abscissa indicate the percentage of parents who reported the resources as being very helpful. The bars extending below the abscissa show the percentage of parents who reported the resource as being not helpful. As can be seen from the overall sample data portrayed in Figure 7.19, family members were perceived as the most helpful.

Figure7.19 Percentage of total sample parent respondents reporting various resources as being very helpful or not helpful.



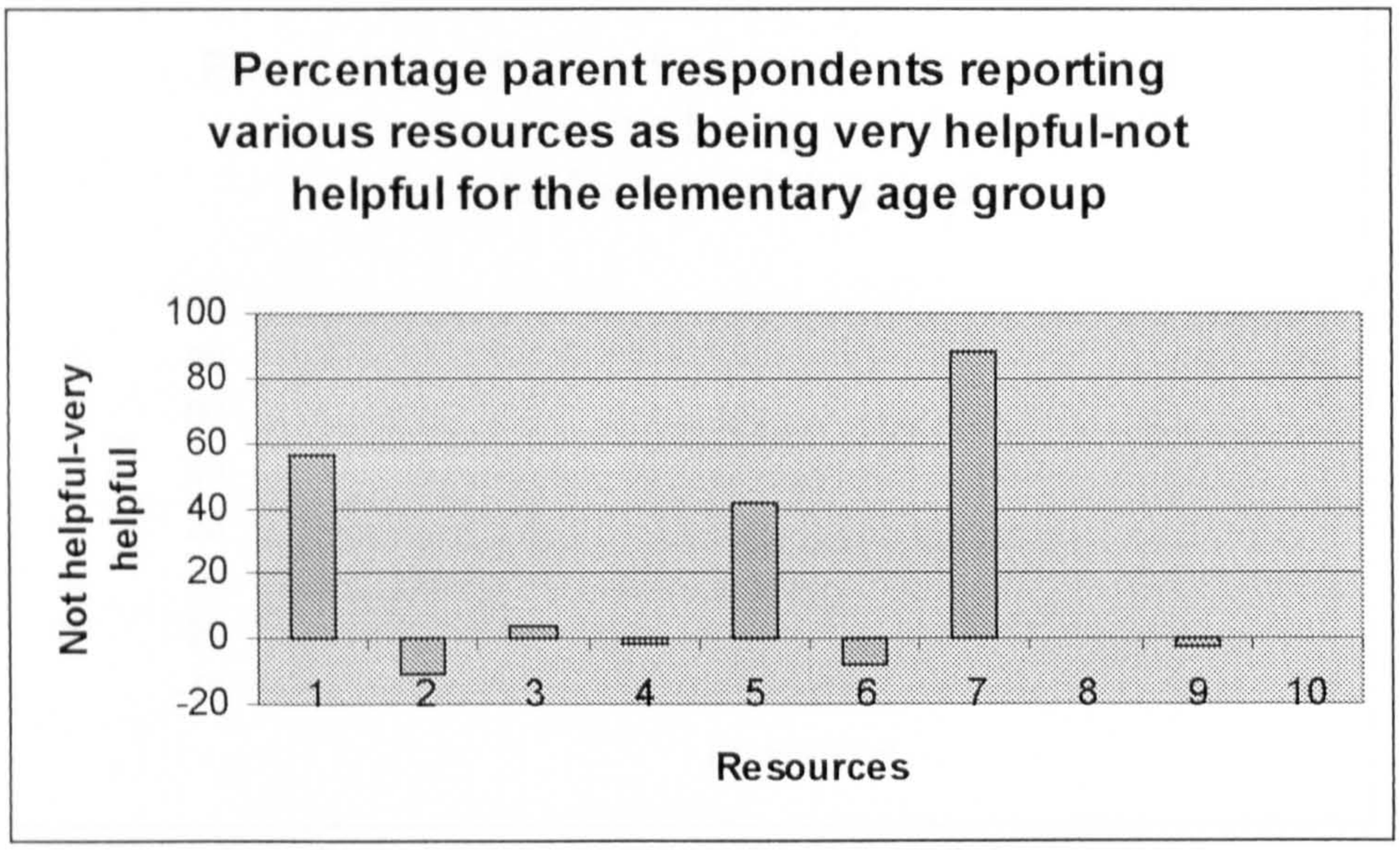
Legend - 1 = Teachers helpful; 2 = Teachers not helpful; 3 = Books helpful
4 = Books not helpful; 5 = Professionals helpful; 6 = Professionals not helpful;
7 = Family helpful; 8 = Family not helpful; 9 = Other; 10 = None.

Figure 7.20 Percentage of parent respondents reporting various resources as being very helpful or not helpful for the preschool age group (Birth to 4 years)



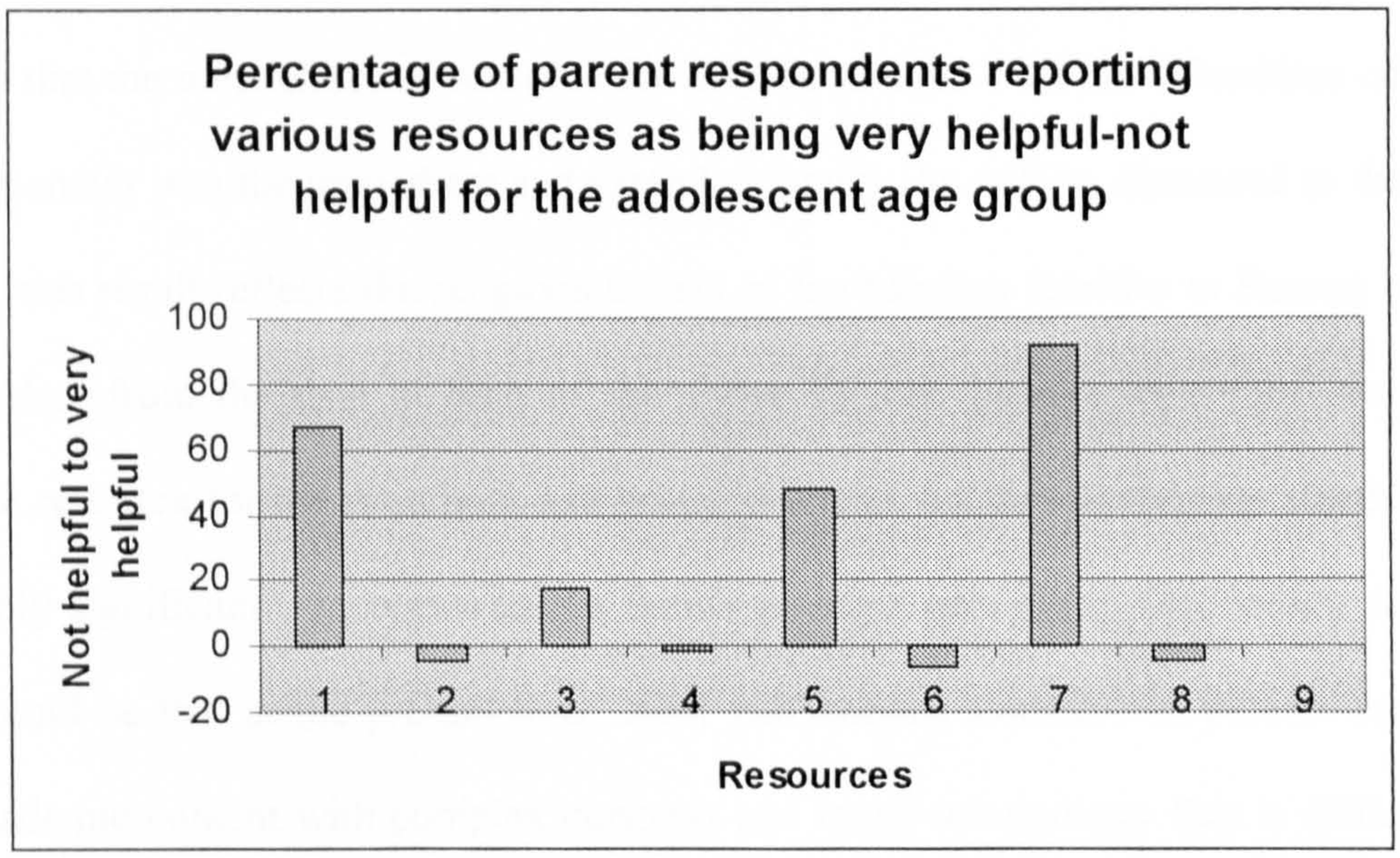
Legend - 1 = Teachers helpful; 2 = Teachers not helpful; 3 = Books helpful
4 = Books not helpful; 5 = Professionals helpful; 6 = Professionals not helpful;
7 = Family helpful; 8 = Family not helpful; 9 = Other; 10 = None

Figure 7.21 Percentage of parent respondents reporting various resources as being very helpful or not helpful for the primary age group (8-11 years)



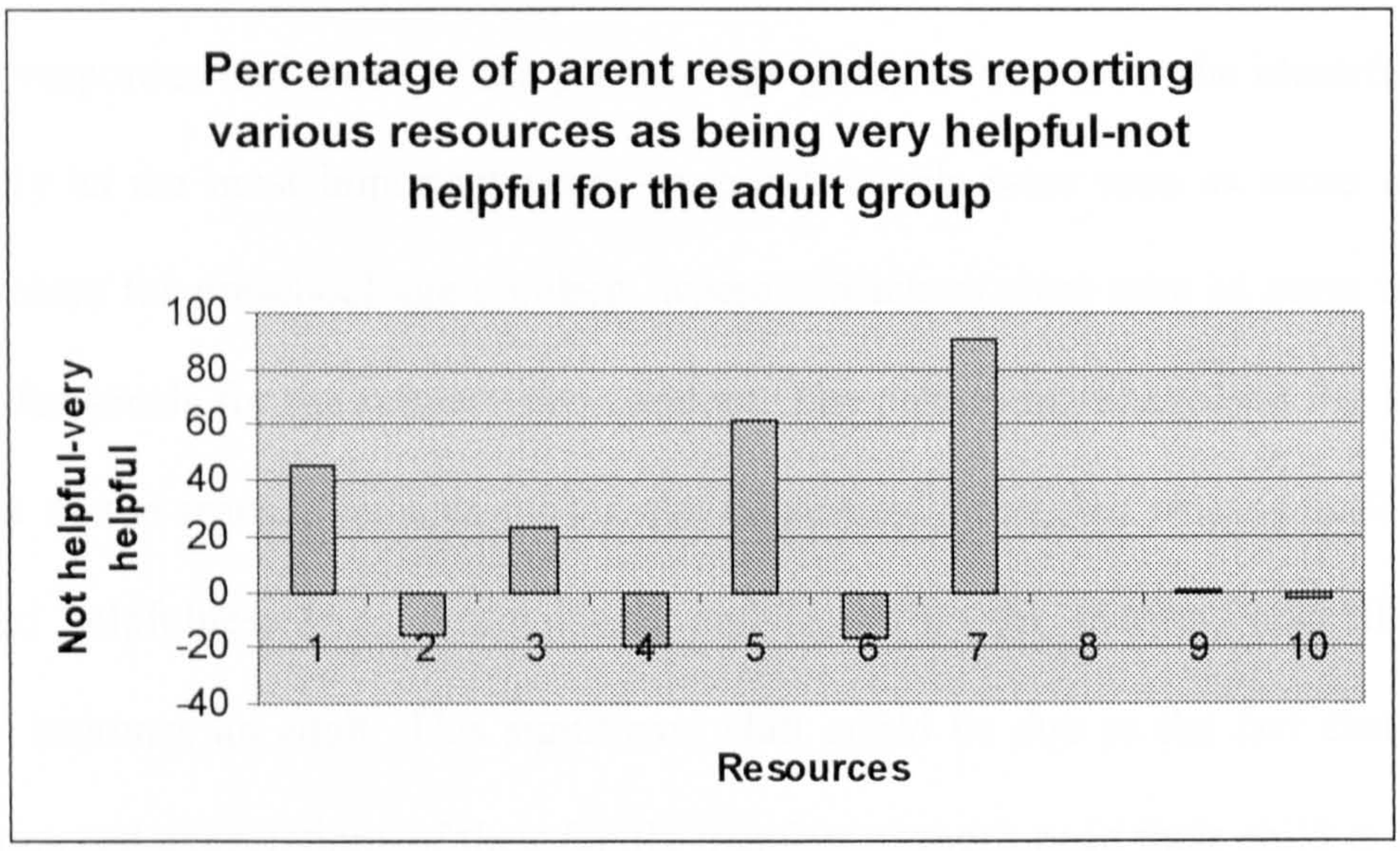
Legend - 1 = Teachers helpful; 2 = Teachers not helpful; 3 = Books helpful
4 = Books not helpful; 5 = Professionals helpful; 6 = Professionals not helpful;
7 = Family helpful; 8 = Family not helpful; 9 = Other; 10 = None

Figure 7.22 Percentage of parent respondents reporting various resources as being very helpful or not helpful for the adolescent group (12-17 years)



Legend - 1 = Teachers helpful; 2 = Teachers not helpful; 3 = Books helpful
4 = Books not helpful; 5 = Professionals helpful; 6 = Professionals not helpful;
7 = Family helpful; 8 = Family not helpful; 9 = Other; 10 = None

Figure 7.23 Percentage of parent respondents reporting various resources as being very helpful or not helpful for the adult group (18+ years).



Legend - 1 = Teachers helpful; 2 = Teachers not helpful; 3 = Books helpful
4 = Books not helpful; 5 = Professionals helpful; 6 = Professionals not helpful;
7 = Family helpful; 8 = Family not helpful; 9 = Other; 10 = None

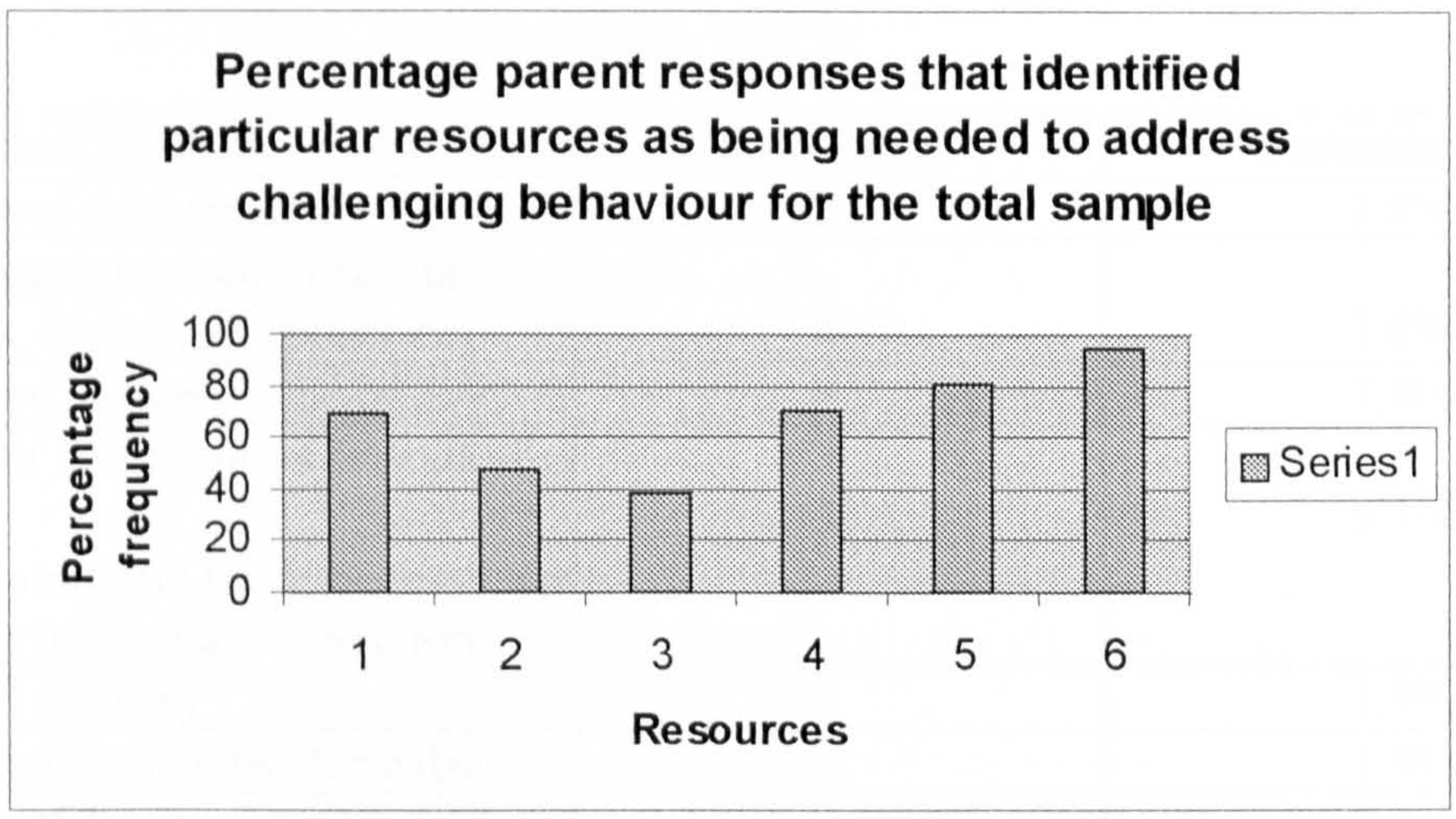
As can be seen from the data in each of the above figures, consistently parents reported that the most effective resource for helping to cope with the behaviours of their family member was the immediate and extended family. As will be discussed in the next chapter, this result reflects the religious beliefs of the Moslem families in Kuwait in this study. Also, from the data in each of the above figures, parents report that the least effective resource for the preschool age group is books, but this perception steadily but not highly significantly increases as the family member gets older. One reason for this result could be that at the present time, most publications available to parents are of a very academic content with complex concepts and much terminology that is difficult to understand. Thus, parents have identified the need for books and published materials to be made readily available, as well as in an easily read format.

Interestingly, there is a change of emphasis between the preschool age group parents' responses and those of the primary age group where, after the identification of the family as the most important resource, professionals were seen as more important than teachers for preschool age children, whereas teachers were seen as more important than professionals for the primary age children. The pattern of reliance on the skills and expertise of the teacher remains during the adolescent years, but reverts back to more perceived helpfulness from professionals and less from the teacher, once the family member becomes an adult. This significant shift could be due to the fact that parents' aspirations and expectations of their family member changes once their child is attending school or is of school age. In Kuwait, teachers are available to continue the education of adults, especially those with special educational needs. Thus, the change of perception of support is significant in this study, but may not have been significant in the western world where generally teaching support is more self selective for adults wishing to re-train or continue their education.

7.6.1.11 Analysis of identified particular resources as being needed to address challenging behaviour.

Resources identified by parents as being needed to help them deal with their children's problem behaviour are indicated in Figure 7.24 below.

Figure 7.24 Percentage of parent responses that identified particular resources as being needed to address children's challenging behaviour..



Legend - 1 = Skill learning; 2 = Professional support; 3 = Readable professional publications; 4 = Strategies for coping; 5 = Respite Care; 6 = Government support

The types of assistance required or perceived as most needed were very varied, with no single category receiving less than 38% response. The most needed resource indicated is Government support, both financial and through resourcing of medical centres and establishing new ones in rural areas. The next important identified resource was respite care, which is interesting given the amount of family and extended family and community support previously indicated. Of near equal importance is the need for the learning of new skills and strategies for coping, which should involve both parents and the family member with autism. Parents further indicated that there was a great need for the professional support of psychologists, behaviour specialists and teachers to help them effectively with their child's behaviour problems. There was a similar pattern across all four groups.

Whilst in conversation with parents, the following problems regarding the pregnancy and birth were noted by the researcher.

Identified Problem	Frequency	Percentage
Threatened miscarriage	2	3.8%
Otherpregnancycomplications (oedema, high blood pressure)	4	7.6%
Premature delivery	4	7.6%
Failure of contractions to start after lo Loss of amniotic fluid, necessitated Delivery by Caesarian Section	3	5.7%
Induced delivery	1	1.9%
Intensive care needed for baby	1	1.9%
Number of families reporting ante-Or perinatal problems	5	9.6%

As stated, although the above was not part of the design of the research these reports are interesting in view of research which suggests, as reported by Ornitz and Ritvo (1976, p.615) that: 'When all prenatal and perinatal complications are considered...they may be significantly associated with autism'.

7.7 Analysis of tape recordings using NU*DIST

As stated in the previous chapter, it was considered essential to identify trends in the usage of descriptors. Therefore, NU*DIST was used because it is a software product designed to assist in the process of qualitative data analysis by handling non-numerical and unstructured data.

7.7.1 Patterns and themes

From the questionnaires and the audio tape recordings, one of the trends which became immediately obvious from the responses was that the sample had strong positive feelings about the impact their autistic family member had upon the rest of the family. Words, such as "continuous screaming", "frightening head banging", "insistence upon regimenting food on the plate", "withdrawing for no apparent reason for hours on end", were frequently used to describe the challenging behaviours which were identified as causing stress. Yet, interestingly such behaviours were denied when parents were asked to respond on the questionnaire. For example, according to the responses there was little or no incidences of autistic family members demonstrating withdrawing behaviours.

Further, words such as feeling hopeless and helpless, blaming oneself (for not being able to control the child), feelings of sickness (when the child deliberately hurt him/herself or bite and kicked family members), and feeling of inadequacy to manage, were frequently used to describe the ways in which parents felt and tried to cope with the unpredictable challenging behaviour of their offspring. This is consistent with the responses to the questionnaire.

Another frequently occurring theme was related to Government support, although until the past three years there has been very little or no restriction on funding for medical conditions. Many of the respondents expressed concern that whilst there were medical centres, these were not conveniently located especially for those parents living in rural areas, or on the outskirts of cities. Within this theme, suggestions of financing travel expenses, and accommodation needed to be addressed, along with the idea of teams of

professionals being located centrally, rather than distributed over numerous government offices and unofficial agencies. Parents stated '*We waste a lot of time going from one government office to another and then to charities. 'X' gets hot and bothered and throws so many tantrums. It would be best if the Kuwaiti Government established one Ministry for Special Educational Needs housed in one building for us*'.

This theme was extended by other respondents, who thought that the gaps in provision should be distributed equally throughout the country and not simply established in Kuwait City. Another pattern which readily became clear in the NU*DIST analysis was that parents felt isolated, although they were grateful for the support given by their families and their extended communities. On further investigation, their feelings of isolation were directly related to not being able to share their experiences with other parents who had autistic children of a similar age. Most mothers felt that they could gain emotional and practical support with the challenging behaviour if they could speak to other mothers experiencing similar problems to themselves. Whilst self support groups were not suggested as these are entirely alien to Kuwaiti society, the gist of the phrases used would suggest such an establishing of self support groups where advice and professional support can be sought along with counselling services. Again, there were distinct traces of compliance with cultural traditions of acknowledging family unity and support, but underneath was a detectable wish by numerous parents, especially the mothers, to interact with other mothers with children of a similar age.

Some respondents expressed the wish for simply written publications and advice books which would help them better understand their family member's condition. '*Not many books we can use to try to find out what to do and where to go*'. '*There's books, but they are too complicated to read*'.

A theme related to some feelings of being blamed for the family member's condition were expressed with the suggestion that an education programme should be broadcast on national television to educate everyone about all medical conditions like autism. '*People just don't understand*'. '*Allah will help us*' '*The Government wants 'x' to learn to speak and read Arabic like his brothers and sisters, but there are no programmes for 'x' to learn from*'; '*How can 'x' learn Arabic, when 'x' does not speak*'?

Many of the respondents consistently described their children's teachers and other family members as the most helpful resource for assisting with the challenging behaviours displayed. Destructive behaviour was most frequently cited as causing continuous stress and strong feelings of confusion. A similar number reported that they, as a family, had developed their own strategies for managing the behaviour of the family member with autism. However, there needs to be research conducted into what the exact nature of what this support consists of and why is it perceived as successful and supportive. Does such support take the form of guidance, or details of practical strategies for handling the difficulties, or is it friendship, understanding and emotional support, or is it simply that such support provided breaks away from the continuous demands of the family member?

Also, research would need to be conducted into why in this study there was a significant increase of destructive behaviour in the adolescent age group as compared with the other groups. As Bristol and Schopler (1984) suggest, for many adolescents with autism, an increase in challenging behaviours is associated with puberty. Or, alternatively is the increase of destructive behaviour in part due to a sense of helplessness or tiredness by the parents and family support so it appears to be worse when in reality it is similar to the challenging behaviour exhibited at an early age?

Equally, further research would need to be conducted to ascertain why some of the resources were not perceived as helpful by some of the respondents and yet others perceived them as being very helpful. For example, professionals were not perceived as being particularly helpful and supportive. Thus, the styles of perceived support and when each identified style or type is most needed, should be investigated to ascertain if there is a relationship between the severity of the challenging behaviours and the perceived helpfulness of resources cited in this study. As stated previously, by ascertaining and identifying which strategies are most helpful to some families who have developed effective coping strategies, these could be adapted to assist other families.

The results of this study, although as already stated caution needs to be taken when attempting to generalise the results due to the restricted sampling, could inform professionals to appreciate the diversity of needs experienced by families. Similarly, whilst the researcher acknowledges that the respondents gave honest answers, the

reliability of the observations and the precision of the responses could not be determined. Thus, the frequency of the challenging behaviours must be regarded as exactly what they are: honest responses to questions that are not validated by direct and independent observations.

7.8 Analysis of the Pilot Study

The researcher wished to compare and contrast the results of the pilot study with those of the main fieldwork, in order to ascertain similarities and differences to increase the reliability of the main fieldwork. Where appropriate the results of the main field study will be recorded in brackets for ease of reference to make comparisons.

Before detailing the description, gender and age of the sample, the following table gives a summary of the descriptive information on the family member with Autism by age group.

Table 7.11 Descriptive Information on Family Member with Autism by Age Group in the Pilot Study (N = 20).

Group	Gender		Mean Age*	Medication	
	Female	Male		Yes	No
Preschool	0	3	2 yrs.1mth (3 yrs 8mth)	3	0
Primary	0	10	9yrs 0mnth (8 yrs 3 mth)	10	0
Adolescent	1	4	12 yrs 10mth 13 yrs 4 mth)	5	0
Adult	0	2	15 yrs 7 mnth 18 yrs 0 mth)	1	1

*In years. Mean age of total sample was 10 years 8 months.

7.8.1 Description of the Sample

In the description that follows figures in brackets ( ) indicate the data for the main study, whose mean age was 13 years 4 months. In total, the families of 20 (52)* children were surveyed in the pilot study. Data on these children were supplied in 4 cases = 20% (17 cases = 13%) by the children's fathers, in 1 case = 5% (28 cases = 54%) by the mother; and in 15 cases = 75% (13 cases = 25%) by father and mother together. The gender and age distribution of the family members, and data on their family background and condition are presented below.

7.8.2 Gender

Similar to the main study, the majority of the children in the pilot study were male 19 = 95% (88%) with 1 = 5% (22%) being female. As with the main fieldwork this reflects the greater prevalence of autism among boys (Aarons and Gittens, 1999).

7.8.3 Age

The children surveyed ranged in age from 2 years 1 month to 17 years 8 months (4 to 17 years), with a mean of 11 years 9 months. Table 7.12 shows their distribution, divided for convenience into four categories: under 6, i.e. those below school age; 6-12, i.e. those in the normal primary/first year secondary school age range, 13+ representing adolescent children of secondary school age and 15+ representing adulthood.

Table 7.12 Age Distribution of Surveyed Family Members in the Pilot Study (N = 20)

Age	Frequency	% ( )*
Under 6	3 (12)	15 (21.6)
6 - 12	11 (27)	55 (52.9)
13 +	4 (10)	20 (18.4)
15+	2 (3)	10 (7.1)

- Brackets indicate the result for the main study with n=52, for comparison.

The reader must remember that the number of respondents in the pilot study is only about one third that of the main study; therefore, direct numerical calculation will not give an accurate numerical comparison. Thus, caution must be exercised. It can be seen from the table that similar to the main study, more than half the sample were of primary school age, while adolescents and young adults together accounted for 30% of the sample as opposed to the main study, where they represented about a quarter of the sample.

Again, caution would need to be taken when generalising the results of the pilot study as the main thrust of the study is parents and their experiences with autistic children who have not yet reached adolescence. As argued above for the main study, puberty and the on-set of puberty may have significant effects on the behaviours displayed by autistic children.

7.8.4 Area Category

All of the pilot study cohort lived in the cities of Hull and Bradford. As support services are reasonably well distributed throughout the UK, it can be assumed that family members are receiving adequate medical, social and financial support.

7.8.5 Number of Siblings

As Attwood (1998); Wing (1996) and others identified specific problems for siblings, the number of children within the family (except for the autistic family member) is detailed below.

Table 7.13 Number of Siblings in the Pilot Study

No. of Siblings	Frequency	%
0	0 (2)	0 (3.8)
1	1 (6)	5 (11.5)
2	1 (14)	5 (26.9)
3	5 (13)	25 (25.0)
4	8 (9)	40 (17.3)
5	4 (6)	20 (11.5)
More than 5	1(2)	5 (3.8)
Total:	20 (52)	100.0

() Brackets indicate the data for the main study.

As the table shows, nearly three quarters of the autistic family members in the pilot study, had three or four siblings and a fifth had four or more.

7.8.6 Age of Siblings

Because of the problems associated with the ways in which siblings compete for their parents' attention, the ages of siblings in the pilot study were ascertained.

Table 7.14 Age of Siblings in the Pilot Study (N = 20).

Age	Frequency	%
0-2	4 (15)	20 (28.8)
3-4	0 (16)	0 (30.8)
5-7	1 (28)	5 (53.9)
8-11	7 (30)	35 (57.7)
12-16	0 (25)	0 (48.1)
17-18	4 (6)	20 (11.5)
19-21	2 (5)	10 (9.6)
21+	2 (4)	10 (7.7)

() Brackets indicate the data for the main study.

Siblings in the pilot study were not similarly distributed to those in the main study, where only a small number of families had offspring who had reached adulthood.

In the pilot study, 40 percent of the families had adult aged siblings. 20 percent of parents had one or more babies or pre-school children to cope with, in addition to the autistic child.

7.8.7 Child Disorder

The distribution of the sample by the disorder with which they had been diagnosed is shown in Table 7.15.

Table 7.15 Child Disorder in the Pilot Study

Disorder	No.	%
Autism	15 (38)	75 (73)
Developmental delay	1 (1)	5 (1.9)
Emotional disability	1 (3)	5 (5.8)
Mental retardation and no autism	0 (3)	0 (5.8)
Mental retardation and autism	3 (7)	15 (13.5)
Total:	20 (52)	100

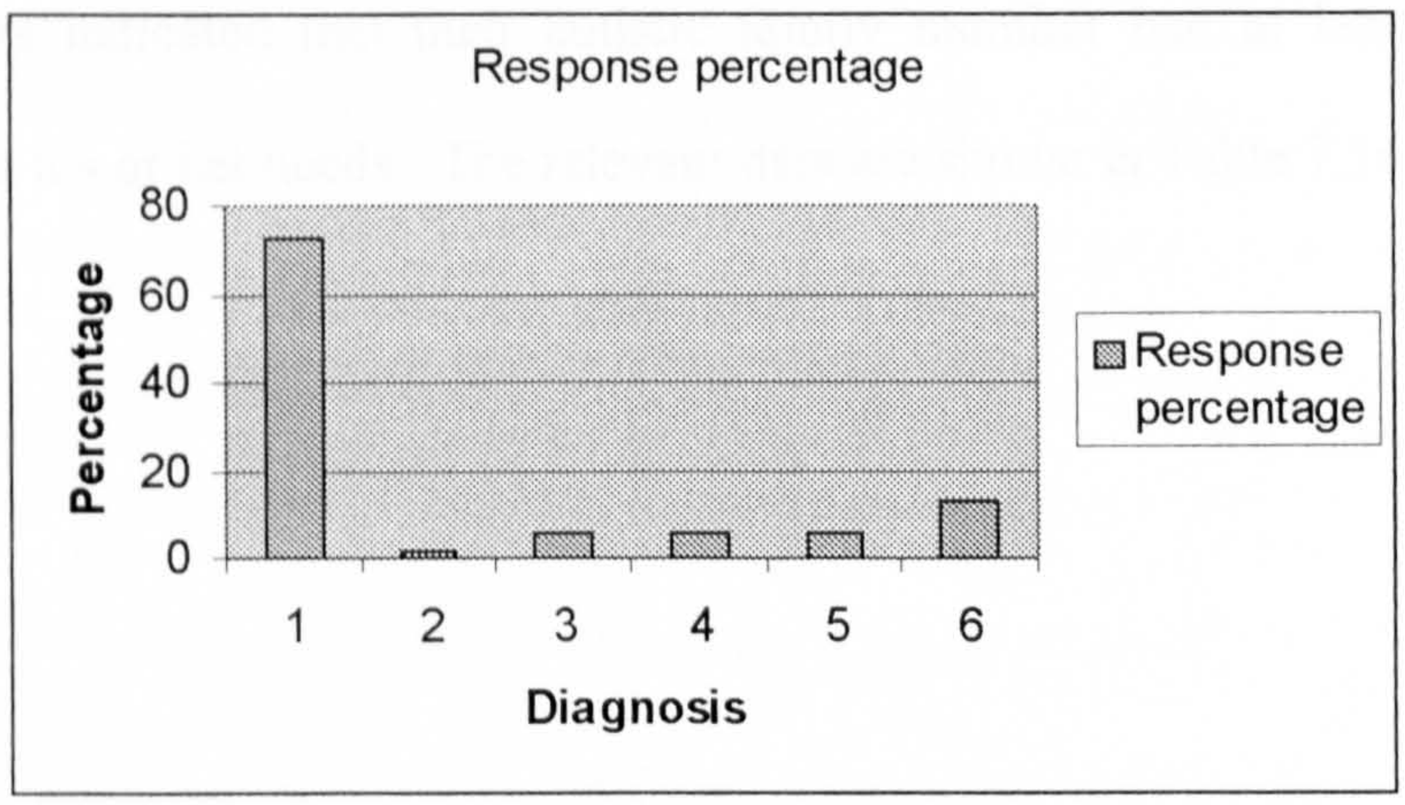
() Brackets indicate the data for the main study.

As the table shows, three-quarters of the surveyed children used in the pilot study had been diagnosed as having autism, while a further 15% were said to have autism plus mental retardation. Unlike the main study, there were no cases in the sample who had diagnoses other than autism.

The above data was accessed from medical professionals in hospital and general practitioners in Hull and Bradford with the permission of the parents. In 80% of cases, the measure used to ascertain whether these children were autistic was the DSM-IV. The remaining 20% had been diagnosed prior to the DSM-IV using DSM-III.

The following is a graphical representation of the data in the table above.

Figure 7.25 Frequency and percentage of diagnosis in the Pilot Study.



Legend - 1 = Autism; 2 = Developmental delay; 3 = Emotional disability; 4 = Mental retardation; 5 = Mental retardation and no autism; 6 = Mental retardation and autism.

7.8.8 Medication

Fifteen (75%) of the sample were not taking any medication. Of those prescribed medications, 4 were taking a single drug, commonly known as Mellerill. 1 was taking two drugs in combination (Nuthera and DMG for example Debakine). Five children were taking vitamins/minerals, either alone or in addition to prescription drugs.

7.8.9 Analysis of Questionnaire Data in the Pilot Study

This section presents the information obtained from the questionnaires regarding the sampled children's communication and self-care capabilities, their behavioural problems, the management of their condition, and the kinds of help to which families have had access. Again, the results of the main study will appear in brackets.

7.8.9.1. Child's Communication of Needs

All respondents indicated that their autistic family member had at least one way of communicating his or her needs. The relevant data are shown in Table 7.16.

Table 7.16 Child's Communication of Needs in the Pilot Study

Method	No.	%
Hand only	1 (15)	5 (30)
Speech only	6 (8)	30 (16)
Crying	1 (3)	5 (6)
Leading Carer	0 (2)	0 (4)
Multiple methods	12 (22)	60 (44)

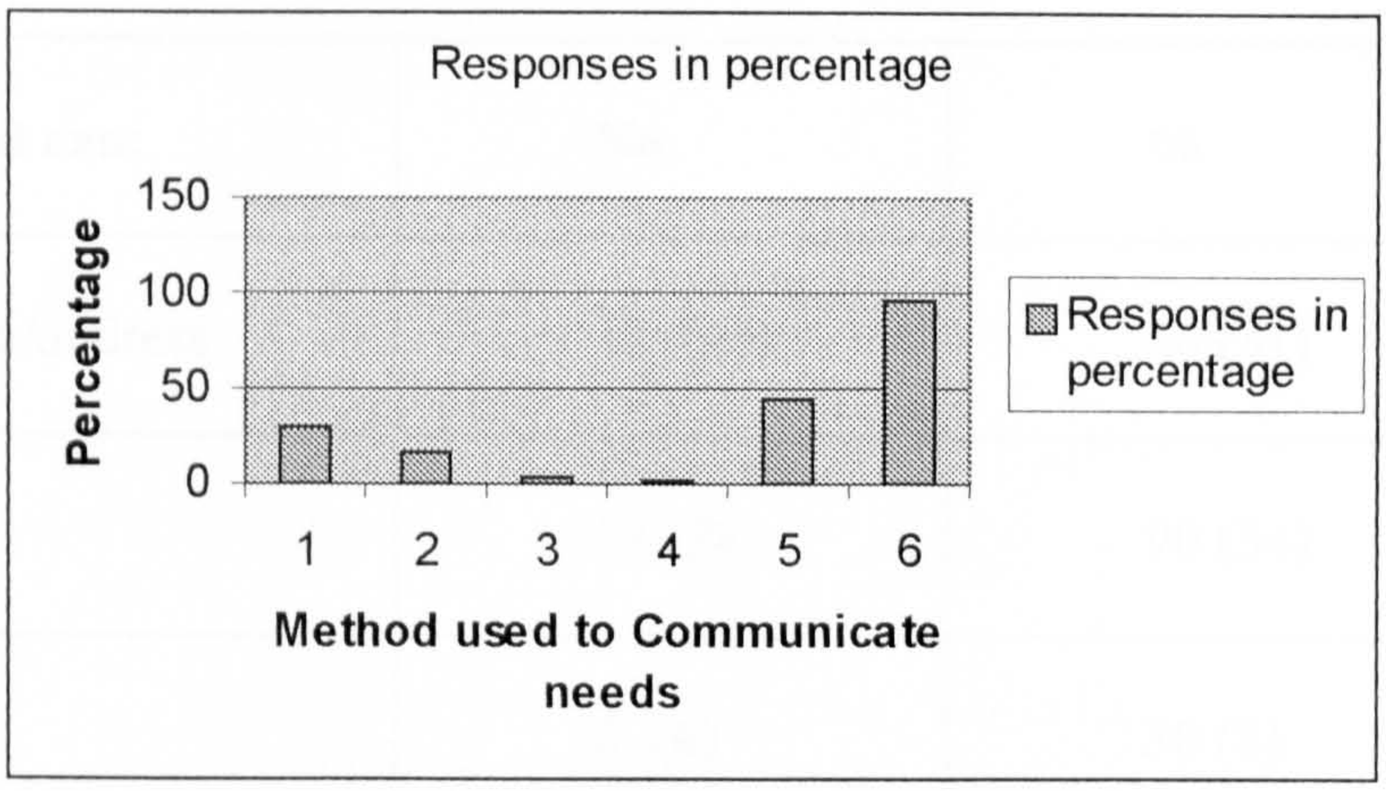
N = 20

() Brackets indicate the data for the main study, N = 50 (see page 182).

Most of the children used multiple methods to communicate need, such as helping themselves, by shouting, gesturing, or leading the carer to what was needed. This was followed by one third using speech only. Similar to the result in the main study, several respondents qualified this answer, saying that the child used "simple" speech or "sometimes says one word", or "cannot use complete, correct sentences".

The following is a graphical representation of the data in the table above.

Figure 7.26 Responses in Percentage to the Method used to Communicate Needs in the Pilot Study



Legend - 1 = Hand only; 2 = Speech only; 3 = Crying; 4 = Leading Carer; 5 = Multiple Methods

7.8.9.2 Ability to perform self-care skills.

Respondents were asked about their children's self-care skills, in terms of ability to dress/undress, eat, bathe and use the toilet without assistance. The responses are summarised in Table 7.17.

Table 7.17 Ability to Perform Self-Care Skills Unaided in the Pilot Study

Child can:	No.	%
Dress/undress	12 (16)	60 (31)
Eat	18 (28)	90 (54)
Bath	6 (4)	30 (8)
Use toilet	18 (13)	90 (25)
Do all of the above.	12 (15)	60 (29)
Do none of the above.	1 (4)	5 (8)

() Brackets indicate the data for the main study.

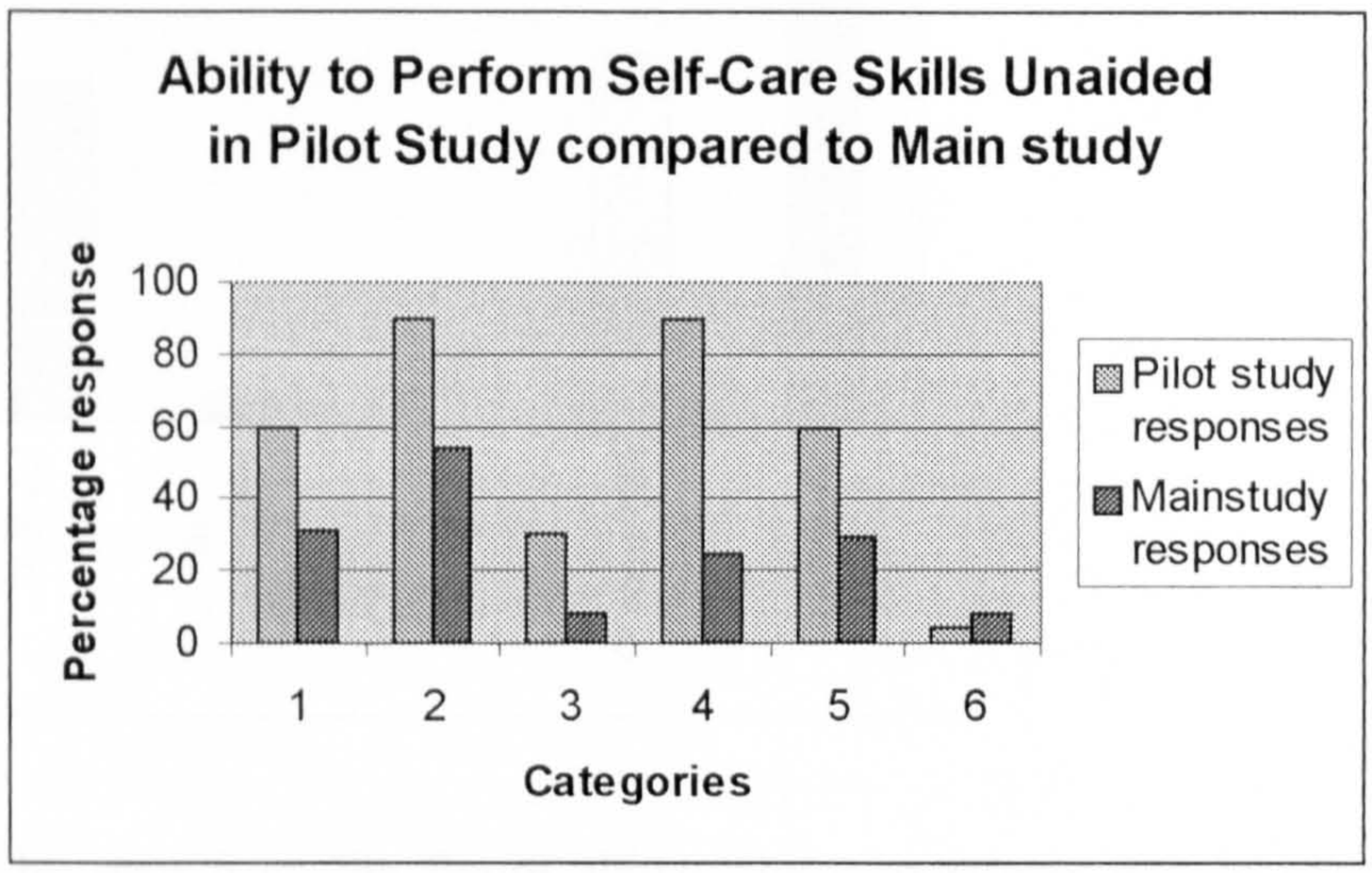
Similar to the main study fewer than a third of the children could attend to all their self-care needs, but most could perform one or two tasks unaided, and others with a little help.

As the table shows, eating was the task which was most frequently performed unaided; more than three quarters of the sample could do this. Bathing was the skill frequently performed unaided by a third of the cohort, though several children were said to be able to do it with help.

Generally, it was the older children (12+) who were capable of meeting all their self-care needs.

The following is a graphical representation of the data in the table above.

Figure 7.27 Responses in Percentage to Ability to Perform Self-care Skills unaided in the Pilot Study and the Main Study.

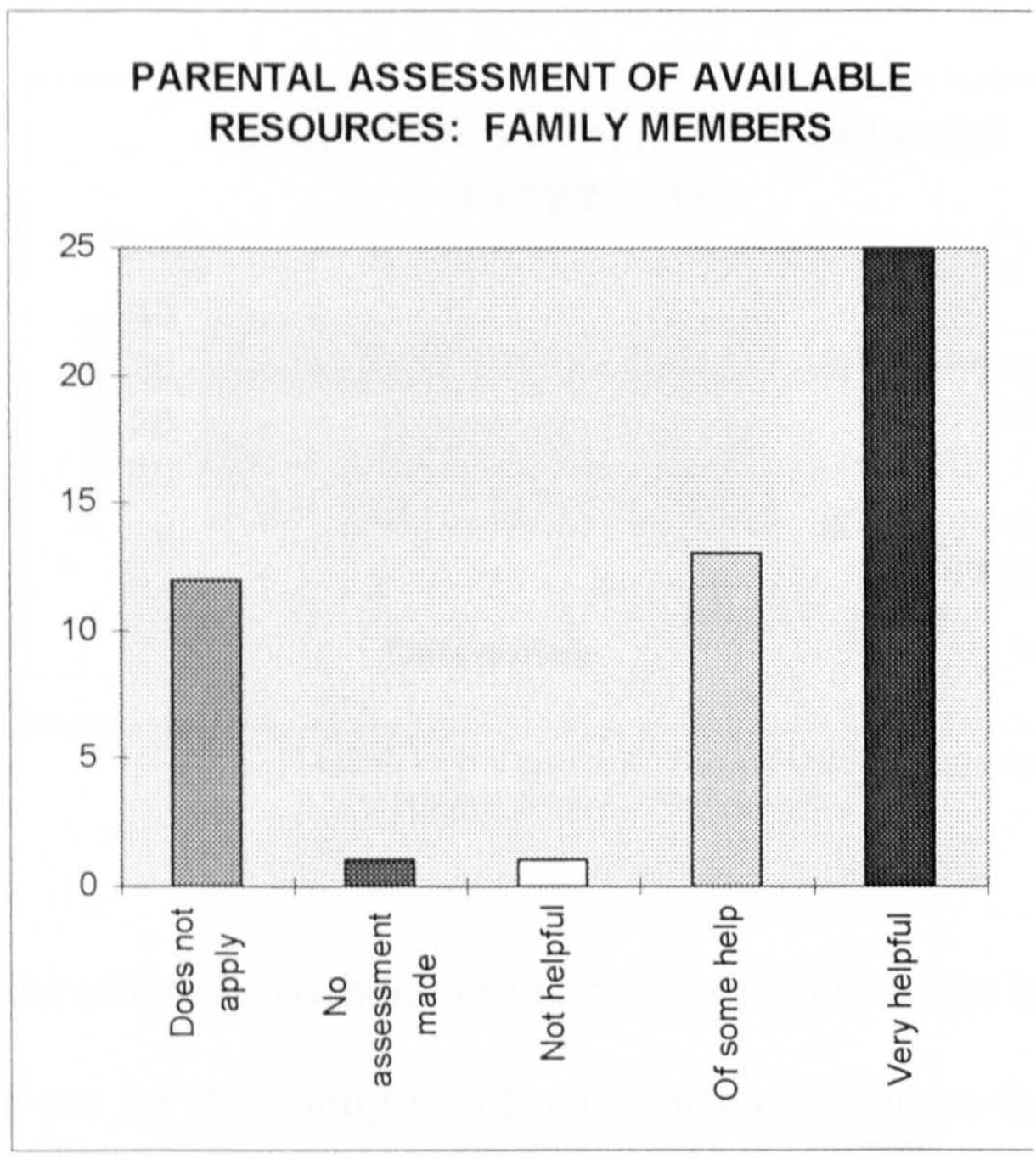


Legend - 1 = Dress/undress; 2 = Eat; 3 = Bath; 4 = Use toilet; 5 = Do all of the above; 6 = Do none of the above

7. 8.9.3 Parental Assessment of Available Resources in the Pilot Study

The following figure is self explanatory as the parental assessment in the Pilot Study is that family support is the most helpful resource available.

Figure 7.28 Parental Assessment of Available Resources in the Pilot Study

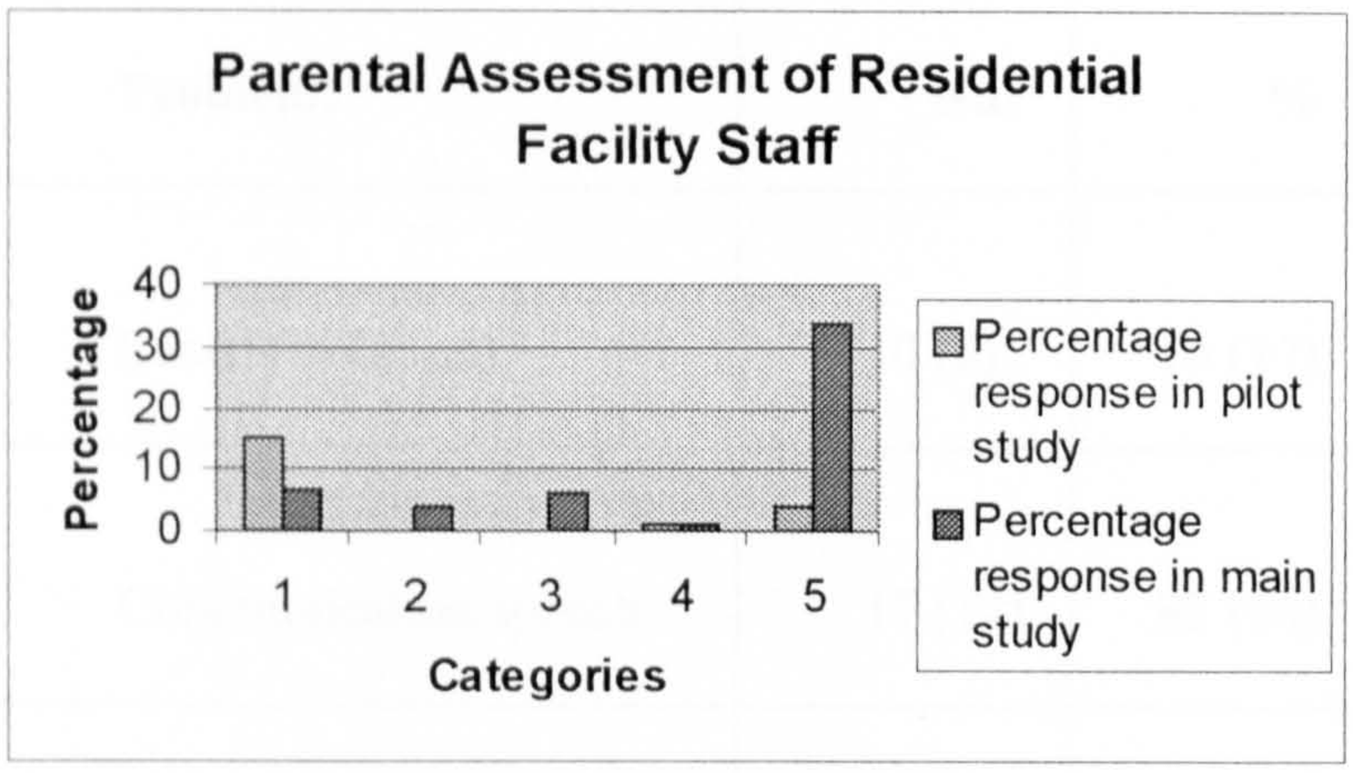


As can be seen from the figure above, the respondents clearly gave a highly significant response to the question related to the availability that the family members give when required. Also, the spread of responses to the other questions give a similar pattern to the findings in the main study.

7. 8.9.4 Parental Assessment of Residential Facility Staff in the Pilot Study

The following figure is self-explanatory as it shows a significant response to help from residential facility staff as being Not Applicable. Again this is similar to the results found in the main study. Because of the cultural and religious traditions that families are responsible for their members, this may account for these results.

Figure 7.29 Parental Assessment of Resources: Residential Facility Staff in the Pilot Study



Legend: 1 = Not helpful; 2 = Of some help; 3 = Very helpful; 4 = No response given; 5 = Not applicable.

As stated above these results may be accounted for because the cultural traditions in Islam are for the family member to remain within the family, as opposed to western culture where there are more choices, e.g. local residential facilities, available.

7.8.9.5 Current Behaviour Problems in the Pilot Study

The table below shows the most frequently mentioned problems. These difficulties were identified as communication/speech, anger and aggression and imperviousness to danger. Similar to the main study, the latter was manifested in such actions as running into the road, climbing onto the roof, picking up sharp objects and playing with electrical wires.

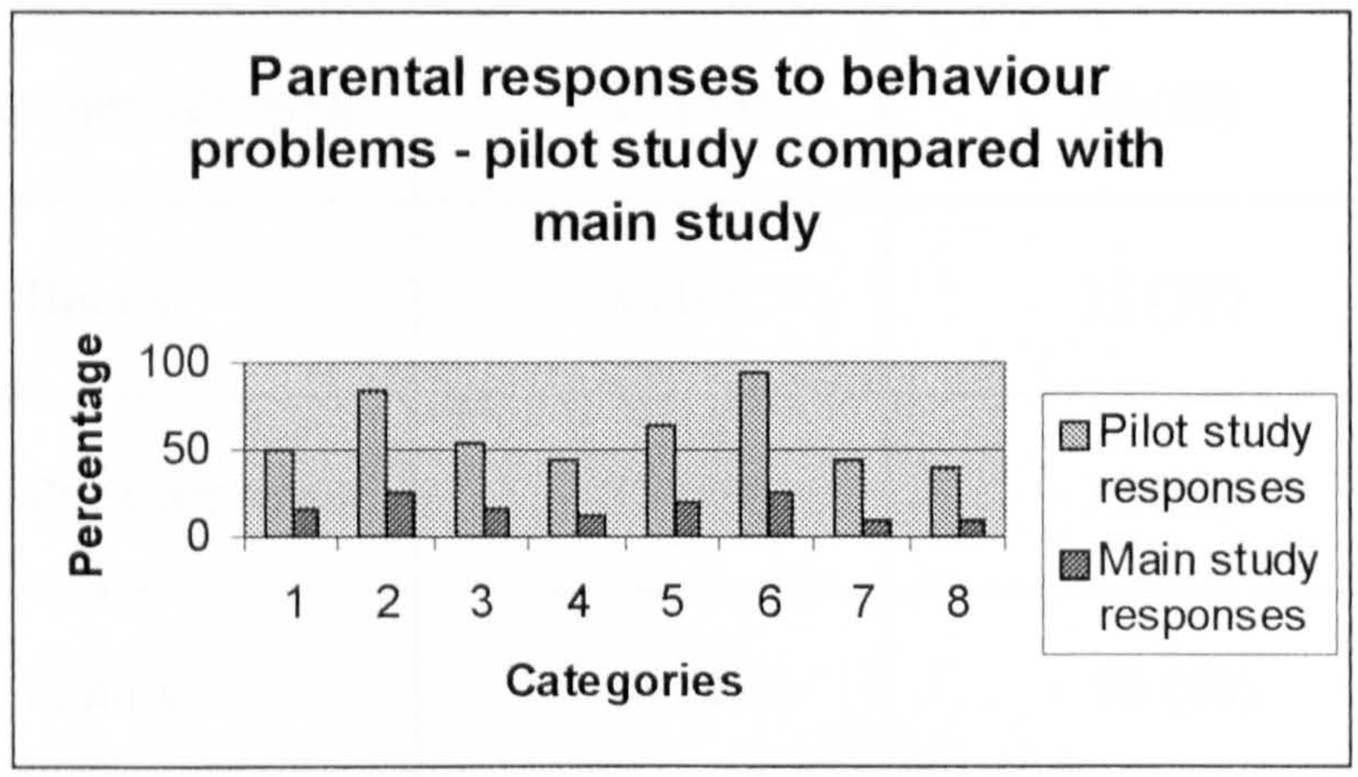
Table 7.18 Current Behaviour Problems (N = 20) in the Pilot Study

Problem:	**No.**	**%**
Social (isolation)	10 (8)	50 (17)
Communication/speech	17 (12)	85 (26)
Obsessiveness/inflexibility	11 (8)	55 (17)
SIB	9 (6)	45 (13)
No sense of danger	13 (10)	65 (21)
Anger/temper/aggression	19 (12)	95 (26)
Destructiveness	9 (5)	45 (11)
Hyperactivity	8 (5)	40 (11)

() Brackets indicate the data for the main study.

Because the number of the samples is different, obviously the percentage for the pilot study will be higher in proportion to those of the main study. For example, in the category hyperactivity in the pilot study, 8 parents responded, giving a percentage rate of 40, whereas 5 parents responded in the main study giving a percentage rate of 11%. If a numerical comparison is taken it can be misleading when the difference in the samples is not taken into account.

Figure 7.30 Parental responses to behaviour problems – pilot study compared with main study.



Legend - 1 = Social (isolation); 2 = Communication/speech; 3 = Obsessiveness/inflexibility; 4 = SIB; 5 = No sense of danger; 6 = Anger/temper/aggression; 7 = Destructiveness; 8 = Hyperactivity.

Because the pilot study sample distribution has only one autistic person represented in some of the categories, information related to the four age group categories as opposed to analysing each attribute was considered unhelpful, and therefore analysis by age group was not conducted.

7.8.9.6 Sources of Help with Child's Behaviour in the Pilot Study

Regarding the main sources of help and support to which parents had access in dealing with their child's problem behaviour in Bradford and Hull, the data are as shown in Table 7.19, compared to the main study results which appear in brackets.

Table 7.19 Sources of Help with Child's Behaviour in the Pilot Study

Source	No.	%
Teacher(s)/school	10 (33)	50 (63)
Books	3 (19)	15 (37)
Professionals	15 (19)	75 (37)
Family	18 (25)	95 (48)
Other	0 (2)	0 (-4)
None	0 (5)	0 -10)

() For convenience to be able to see immediately comparisons between main study and pilot study brackets indicate the data for the main study.

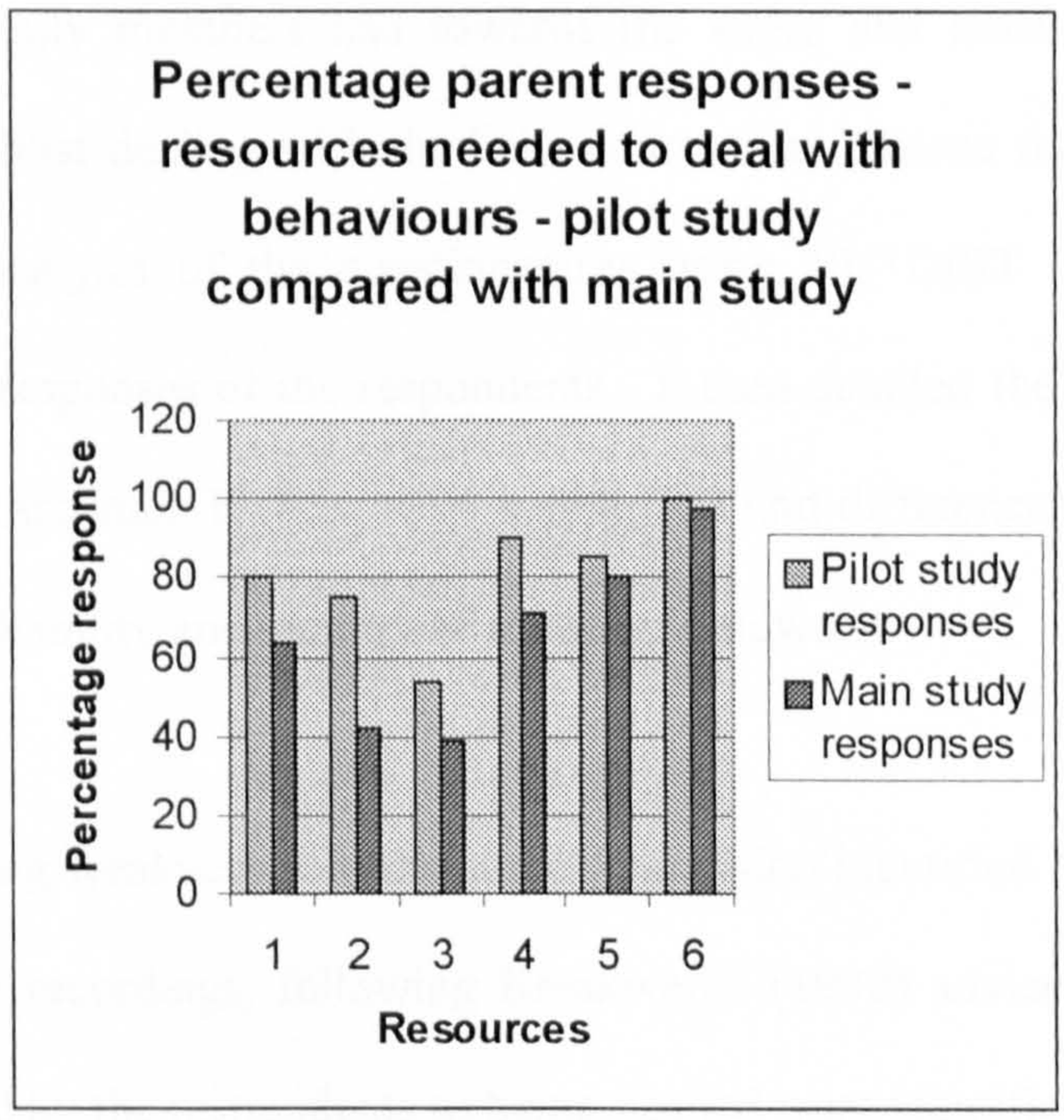
As the table shows, the main source of help, used by nearly one hundred percent of families, was the family. Next came the professionals, cited by almost three quarters of

the sample. Books and professionals (doctor, psychologist, etc.) were each found to be of little use to the pilot study cohort.

7.8.9.7 Analysis of identified particular resources as being needed to address challenging behaviour in the Pilot Study.

Resources identified by parents as being needed to help them deal with their children's problem behaviour are indicated in Figures 7.31 below.

Figure 7.31 Percentage of parent responses that identified particular resources as being needed to address children's challenging behaviour in the Pilot Study.



Legend - 1 = Skill learning; 2 = Professional support; 3 = Readable professional publications; 4 = Strategies for coping; 5 = Respite Care; 6 = Government support

The above figure demonstrates that parents in both the pilot study and the main study identified the need for more government support as being the principal resource

they required in order to deal with the behaviour problems of their family member. The pilot study parents then identify different needs from those of the main study. This may be accounted for because the availability of the resources in the UK is different from those experienced by parents in Kuwait. Thus, the main study parental response can be used to identify the current situation in Kuwait as perceived by the cohort of the main study.

7.9 Summary of the Chapter

This chapter has explored through qualitative and quantitative analysis, the data collected and collated from the questionnaires after the demographic analysis, to find what perceptions family members had towards the stress and stress related problems they experienced whilst dealing with the behaviours of an autistic family member. This was followed by analysis of the questionnaires using NU*DIST to explore patterns and themes in the responses of the respondents. It then detailed the data collected from the pilot study, to ascertain if there were similarities and differences between the results, to increase the reliability and validity of the main fieldwork.

Regarding weaknesses in the current provision identified by the questionnaire and the audio tape recordings, following Breakwell's (1990) advice, all the changes which were perceived by the respondents as being needed were identified and tabulated below.

Table 7.20 Weaknesses in the current provision

Weakness in current provision	Suggested solutions
No rural facilities	Establish local centres in all areas of Kuwait
No centralisation of government agencies to provide support	Establish in one building all the agencies who provide support so that they can work co-operatively. Also, by centralising them together it will be much easier for parents to gain information and financial support they need.
Lack of up to-date data on the severity and incidences of autism.	Establish a national database which is accessible to government agencies, and researchers.
Lack of financial support.	Establish an annual specified amount of Kuwait dinars to be used only in the support and provision of services for autistic citizens.
Lack of public awareness.	Establish various types of public awareness events through television, locally held education fairs.
Lack of co-ordinated diagnosis.	Establish centres specifically staffed with experts in the diagnosis of autism to standardise reported cases.
Lack of medication and information Related to alternative therapies.	Establish within the centres and hospitals standardised medication for the various attributes of autism. Also, ensure that parents, doctors and carers are aware of alternative therapies being used in other countries. Keep this information bank up to-date.

In the next chapter, a discussion of these findings will compare and contrast them with the results of research covered in the Review of Literature. However, the researcher believes that further research within Moslem countries is essential in order to identify aspects

specific to such cultural environments, and what, if any, have significant impacts on the rearing of autistic children. To date this has not been undertaken.

Chapter Eight

DISCUSSION OF THE FINDINGS

8.1. Introduction

In the preceding chapters, the current understanding of autism has been reviewed and aspects of the education and management of autistic children reported, with specific reference to the impact autism has on the family, and the provision recently made available in Kuwait. This chapter aims to discuss the findings of the study, comparing the observed treatment of the syndrome between Kuwait and the western world and how this impacts on the family.

8.2. Discussion

8.2.1 Incidence of autism

As stated previously, the recorded incidence of autism in the population depends crucially upon how it is diagnosed and defined. Briefly, research has shown that studies from America, Japan and France (Bryson *et al*, 1988; Tanoue *et al*, 1988; Ciadella and Mamelle, 1989 respectively) suggest that autism is found throughout the world, and is not more common in any one society or social class than in another. The incidence of autism in most studies appears to be around 4-10 autistic children in every 10,000 live births. This means there may be over 500-700 autistic children in Kuwait. With an additional 3,000-4,000 children with varying educational and physical disorders, it is of paramount importance, therefore, that this point is acknowledged and that all children in Kuwait are screened as effectively and as early as is practicable.

Ways in which this might be achieved are by following the established systematic identification and referral procedures comparable to the UK statementing system. Also, Van Krevelen's theory outlined on page 36, could be used as a base line assessment. There is a case for Kuwait to screen all 3 year old children, because autism is rarely reliably diagnosed before this age, therefore, it would seem sensible to set up screening procedures. Doing this would allow for early detection of autism, as well as many other

disorders. The sooner disorders of any kind are identified, the sooner it would be possible to give appropriate support.

Further, Wing (1988) reported that Asperger claimed that the incidence of autism is more frequent in males than females. Because of this fact, there would seem to be a need for diligent monitoring and assessing of male 3 year olds as standard practice. Likewise, in view of the changes which generally occur as children grow older, resulting in some problems identified at 3 years of age becoming less marked and some disappearing altogether, there would need to be at least, annual review panels set in place, if not 6 monthly review panels depending on the severity and incidence of the handicaps involved (Fields, 1995).

This screening could be implemented by using the DSM-IV procedures outlined in Appendix A, for qualitative impairment in reciprocal social interaction and impairment in communication and imaginative activity. This would enable all agencies concerned with autistic children to establish exactly where the child is on a continuum assessment ranging from mild to severe. Also, because the majority of children with autism have additional learning difficulties, many of which are severe, these may be identified and dealt with separately and in addition to the recommended support for autism. By approaching the disabilities from two or three angles this must inevitably aid the patient.

In regard to what these procedures might be, as the review of literature has indicated, by the end of the 1980s, a consensus of agreement was reached, when Burd and Kerbeshian (1987) suggested five features of Asperger's syndrome for screening (see page 23). Whilst these could be used it must be remembered that Szatmari *et al* (1989) suggested a more flexible selection of criteria as outlined in Table 2.1. However, these do not take into consideration underlying handicaps which may be compounding the

diagnosis of autism. So research into this could be undertaken and Kuwait could develop a new but different assessment procedure based on the previous results of international research. It is envisaged that such assessment programmes as the Checklist for Autism in Toddlers (CHAT) could be effectively incorporated and implemented because they are based on current theories of behavioural and cognitive corrective techniques (Fields, 1995). All children should be monitored, assessed and comprehensive records kept once suitable criteria have been identified to ascertain special educational needs.

Briefly, as stated above, all the epidemiological studies show a significantly greater number of boys than girls with autism: male to female ratios vary from 2:1 (Ciadella and Mamelle, 1989) to almost 3:1 (Steffenburg and Gillberg, 1986).This was found to be true of the results of this study in Kuwait. Most girls with autism are at the lower end of the ability range, while at the more able end (Asperger's syndrome) boys may out number girls 5:1 (Lord and Schopler, 1987). Relevant research in Kuwait could be authorised into the effectiveness of behavioural therapy as well as the fragile-X-linked chromosome. This is because, as Szatmari and Jones (1991) suggest, there may be some possible reasons for the lower IQ of females with autism. With this information, academic and clinical research into this relationship would be advantageous.

Because there is evidence for (a) a genetic component in autism (Rutter *et al*, 1990), (b) a significant familial loading for autism (Smalley *et al*, 1988), plus (c) Bauman (1990)'s research into the study of autopsied brains of people with autism where he found abnormalities in the limbic and cerebellum, perhaps the development of Magnet Resonance Imprint (MRI) scanning could be used with infants and young children to detect malfunctioning parts of the brain (Fields, 1995). Similarly, EEG testing for epilepsy in Kuwait could become standard as Olsson *et al* (1988) collated a high incidence of epilepsy in autistic children.

As part of a comprehensive screening programme to be implemented in Kuwait, it would be necessary to implement screening of the siblings of autistic children, as they showed a significant increased incidence of other cognitive impairments, such as language disorders and social impairments (August *et al*, 1981). Finally, in regard to screening procedures, as research has reported that mothers of autistic children had more problems during pregnancy and delivery than mothers of children who later developed schizophrenia (Green *et al*, 1984) this would suggest that there is an essential need for research into the pre and perinatal difficulties during pregnancies in Kuwait in order to identify and highlight early incidences of autism from birth. Incorporating into such automatic screening procedures all of the symptoms criteria cited in previous chapters, could go to make a new but more comprehensive overlapping criteria diagnostic measure, which will assist in ascertaining the individual needs of children in Kuwait in general and of autistic children in particular.

Setting up teams of professional help, such as paediatricians, social workers, counsellors etc., in various geographical districts in Kuwait, would minimise the time factor involved in diagnostic procedures (Fields, 1995). It is seen as imperative that there is trust, co-operation and a willingness for the well-being of the child, between the doctor, his/her colleagues and the immediate family.

In tandem with the above, there would need to be comprehensive monitoring procedures set in place. For instance, if the first-born child is screened and found to have autism or any other disability, then close monitoring of the siblings and relations within that family would be necessary. As they may live in different parts of Kuwait it would be essential to have this information on a central data-base, in order that it could be available to all concerned (Fields, 1995). Because at the present time in Kuwait, it is up to the

parents of the child to bring his/her case to the notice of his/her own doctor, there are differences in terms of the access route to such provision between the Western world and Kuwait. Whilst children are being screened for a variety of childhood illness, it would be advantageous to identify and access special needs through on-going medical examinations of all children up to the age of 10 years. Children with special needs then may be referred by doctors, or teachers or parents, but not necessarily as urgent cases. Perhaps a profiling case history could be developed on an Internet computer system within Kuwait only, which would quickly but effectively inform the agencies of the child's medical history as well as that of siblings and extended family (Fields 1995).

A number of reports have suggested that the association of autism with social class may be an artefact caused by the greater likelihood that middle-class parents will get their child seen by a specialist (Wing, 1980; Gillberg and Schaumann, 1982). If this is so, there must be, therefore, an all out effort to inform and educate poor families in Kuwait about this disability. Providing support similar to that enjoyed in the UK, such as attendance allowances, travelling assistance and quick, efficient access to agencies related to the disability, would be very beneficial to Kuwaiti citizens in the lower income brackets.

Poorer families could be provided with special grants to assist with the cost of travel to centralised centres, as well as overnight accommodation, which might be made available if it is necessary to retain the autistic child overnight (Fields, 1995). Self sufficient support groups could initially be organised by various government agencies, and then once established they could become self supporting, meeting the need specific to their area. Also, perhaps a team of administrators could be sent to other countries to discuss the advantages and disadvantages found in the development and evolution of the systems used.

8.2.2 Quality and Quantity of Provision and Funding

As stated in Chapter Four, one of the most striking observations to emerge is that in Kuwait, the situation with regard to provision for special needs in general, and autism in particular, is somewhat confused and fragmented, compared with that enjoyed in the western world. This may be because in the UK, a clear legal obligation for local education authorities to provide for special needs exists under the terms and conditions of the 1980 Education Act, The Code of Practice and the provisions in the Dearing Reports 1994/5. Similarly, in the USA there are clear legal obligations specified by governmental legislation. Likewise, there are various sources of community support and information in existence in these countries. Kuwait could explore these and develop similar sources specific for its citizens. For instance, in Kuwait, because the recognition and understanding of autism is still very much in its infancy, there is no National Society for Autism or similar body, such as exist in many other countries. Such bodies can, as western experience indicates, make a major contribution in providing advice and support to parents and teachers, and generally raising public awareness. Parents of a child with special needs may often feel isolated, and need a variety of emotional and practical support. Some schemes operating in the UK and USA were briefly indicated in Chapter Three. There is, however, no evidence of such schemes as yet in Kuwait. It would seem paramount that the Kuwait government develop appropriate legislation in line with those cited above in order to make a clear codification of responsibilities for meeting special needs *per se* and meeting the specific needs of its autistic citizens.

Whilst, in Kuwait, the government has taken upon itself a general obligation to provide for the social welfare of all its citizens, provision for special needs in general, is scattered across many different agencies, both official and non-official. Because such a situation is likely to cause confusion as to exactly what is available, as well as to leave

gaps in provision, it might be preferable to have a central agency to cover all special needs. This could be evolved from the existing Kuwait Society for the Disabled; the Disabled Care Homes, who cater for severally mentally or physically disabled, being combined with the Social Rehabilitation Centres, who serve 275 citizens with mental disabilities. Within that agency there could be sub-sections with responsibility for specific disorders, such as autism. Doing this would enable parents, teachers, medical staff etc. to be able rapidly and efficiently to gain all information required, as well as appropriate financial and moral support. With only one agency dealing with the problems, this would inevitably lead to financial savings. However, until such special educational needs provision is centralised under one Ministry, there is very little anyone can do to reduce the inevitable doubling up of manpower and expense, and the omission of provision in certain areas.

Much, also, can be learnt from the fact that in UK and USA, arrangements to cater for special needs, including autism, are distributed reasonably equally throughout the country. As stated in this study, in Kuwait, provision is so far confined to one or two urban centres, so there is a need for a feasibility study to be conducted to see where geographically these centres could be placed (Fields, 1995). Within these centres, relevant training programmes and counselling facilities for parents and families, and members of the wider community could take place, because, as Fields (1995) states, the better the understanding and acceptance of autism, the better the chances of integration into society will be.

The different approaches to provision are also reflected in funding arrangements. In UK and USA, provision is government local authority financed (though with community contribution levied via the taxation system), whereas in Kuwait, as seen in Chapter Four, provision, even within a single situation, may be financed by a

combination of government grant, private endowment, charitable donations and tuition fees. It would seem appropriate that all areas of funding, resourcing, and setting up adequate centres in geographical districts, which have a high predominance of autism, could be explored.

Also, although schools and teachers often have their own ways of dealing with the educational needs of autistic pupils, it is essential that parents be informed and educated about different strategies to cope with the specific needs of their own children. Whilst not advocating uniformity, it would be an advantage to follow a core structure of how to deal with such children rather than an *ad hoc* system as at present (Fields, 1995). Many parents, and the extended families of such children, have no or little experience or knowledge of autism. By producing such advice, unnecessary stress and feelings of failure to cope could be minimised. Counselling of families could perhaps be incorporated into the overall plan for Kuwait in dealing with special needs, as so often the other children in the family suffer because of the time and effort needed to be given to autistic siblings. Educating the populace as to the specific needs of families coping with an autistic member could help such families to gain an extended support system through local communities and fellow members of local Mosques.

Ignorance and cultural factors perpetuate the stigma which, in many people's eyes, is still attached to those with special needs. This stigma increasingly isolates the parents and the family of autistic children. There would seem to be a need for the leaders of Islam in Kuwait to totally denounce this stigma. and establish support groups for parents and families, along with the need for relevant information and training to be an integral part of initial teacher training in the various courses at the University of Kuwait. Ensuring that current and future students of the University are informed about the multitude of behaviours and strategies for coping with the full continuum of autistic

children, could help to further educate the whole populace of Kuwait. Hence, more information and public awareness is needed, in order to maximise the support available to autistic children and their families. This could be done at the school level, the university and college level, mosque level, public information and television level. Through implementing all of these, as Fields (1995) argues, understanding of autism, and hence, the integration and acceptance of its sufferers, and support for their families, would be increased.

8.2.3 Academic Research in Kuwait

With the high output of oil resources from the Kuwaiti oil fields, perhaps a designated amount of monies could be allocated as a governmental budget specifically to cover all special educational needs. This way, disabled people and their families will know that a consistent number of Kuwaiti dinars is available each year to support them and their children. The spin off effect would be that voluntary agencies will not need to be reliant on fluctuating fund-raising and charity donations. This would allow them to concentrate their hard work efforts on heightening awareness and improving the conditions for such Kuwaiti citizens. Further, with the stress of having to raise funds to support various projects removed, much more time would be available to be spent on clinical research into the causes of Autism (see below for fuller details). In tandem with the above there could be many opportunities for the development of Kuwait's special needs programme by close collaboration with Saudi Arabia, which is making numerous efforts to address the problems of special needs within that society (Fields, 1995).

In the field of academic research, government monies being made available would help enormously in the development of more research possibilities through governmental funding thereby encouraging comparative studies of research. Perhaps relevant research done in the western world could be replicated in Kuwait to find out the similarities and

differences and contribute to the international understanding of autism. Or, based on the results to date, biochemical research into the fragile-X chromosome could be developed along with brain functioning experiments in a bid to identify brain damage or brain mal-functioning causes of autism.

Similarly, with Wing's (1988) introduction of a concept of a spectrum of disorders in autism in order to capture the idea of a range of manifestations of the same handicap, research could be conducted in a parallel fashion to this in Kuwait, in order to ascertain if such a concept really exists, and if so, to what extent such a concept can assist in identifying, supporting and eradicating some elements of autism. The methods to be used for such research could be either prospective studies, which allow the researcher to decide which early behaviours to monitor, and are therefore, free from hindsight (Fields, 1995), or using the criteria cited throughout this study a new set of criteria be developed to monitor autistic orientated behaviours.

With the use of modern technologies, Fields (1995) suggests that camcorder recording downloaded onto computers could be a way of monitoring, analysing and collating social and cognitive behavioural elements of autism in comparative international studies utilising computer programs such as NU*DIST. Likewise, she suggests that much use could be made of existing computer software packages developed for special needs children in the Western world to encourage language development etc. As most of these packages are highly pictorial with over-voice, she suggests that it would not be a difficult procedure to over-voice the programmes with spoken Arabic, thus coming in line with the legislation of Kuwait, that the emphasis should be on using Arabic as a spoken language with all disabled citizens.

Further research could be conducted in the area of drug therapy as the results to-date are inconclusive because of issues related to medical dosage, and experimental issues, such as sample groups are too small so there is a lack of control comparison. Also, she suggests that as there is a lack of objective measurements of appropriate independent and dependent variables, there could be much research into this aspect of autism and its pedagogy. Fields (1995) states that there is an important role for research into the role of clinicians in the treatment of additional handicaps and the alleviation of secondary behaviour problems, such as sleeplessness. With the different approaches to the treatment of autistic children in the categories of psychodynamic, pharmacological and behavioural she suggests that research into the similarities and differences of these treatments in Kuwait could be most enlightening.

Finally, in regard to research, the importance the environment seems to play in the responses of autistic children (Schreibman, 1988), could be explored in ways such as Fields (1995) suggests, i.e. animal centred orientation, fibre-optic stimuli, music and pictorial stimuli for young children, adolescents and adults, including residents in group homes, transition homes and other community-based resources. She is of the view that an interesting comparative study could be set up and executed effectively in this area. Also, all the areas of research outlined in Chapter Three would need to be implemented in order to contribute to the international and Kuwaiti understanding and management of autism. This would be especially in the area of which intervention programmes are more effective and why they are, and how could these be improved upon to meet the specific needs of an Islamic nation.

It needs to be said that, whilst there are many improvements needed, it was encouraging to observe that the new institutions catering for autistic children in Kuwait, include parental support and are attempting to try to increase public awareness in their

objectives. These small steps will inevitably lead to large strides in Kuwaiti understanding, leading to national and international understanding of the needs and provisions of autistic children.

8.2.4 Comparison between the western world and the findings in Kuwait.

a. In the western world

In the mid-1970s, most educational systems were not very responsive to the needs of autistic children and many autistic children were denied access to public schools' programmes (Schreibman, 1988). This resulted in many autistic children being placed in inappropriate residential institutions. But in recent years, Local Education Authorities are required by law to meet special educational needs, either by making additional resources, such as support staff, available in a mainstream school, or by providing education in a special school or unit. Thus, Jordan and Powell (1995) published Jordan's personal views as well as her work commissioned by the UK Department for Education and Employment (DfEE) to review educational interventions for children with an autistic spectrum disorder.

The main aim of this review was to provide good information on the value of the various approaches in order that parents would be better able to determine which was the best for their child. Autistic children vary considerably in academic capability and behaviour. Thus, depending on the degree and nature of the child's difficulties, their needs may be met by either a special school for autistic children, a school or unit dealing with language disorder, or a school for moderate learning difficulties. The progress of all

autistic children is reviewed annually and continuous monitoring of their progress is maintained. (Aarons and Gittens, 1992). And as Jordan and Powell (1995, p. xi) state

> There is no reason to suppose that the child with autism is able to benefit from...an early developmental curriculum...beyond the mechanical rote learning of skills, which will be unrelated to understanding and therefore difficult to generalise or extend...Professionals and parents need to work within the context of the autism.

Although Jordan and Jones (1995) and Schopler *et al* (1980) view the autistic child as unable ever to become non-autistic, not all researchers agree. For example, Howlin, Baron-Cohen and Hadwin (1999) outline a strategy for addressing one of the major deficits in autism, that of being unaware of the thoughts and intentions of others. Howlin *et al* (1999) report that from their findings there was a significant change after only a very brief training period, and they found that these improvements were maintained for some time after the learning intervention.

Moreover, Greenspan and Wieder (1998, p. 479) advocated a strategy based on interactive play for addressing the lack of social awareness of autism. They described about half of their sample as becoming '...spontaneous and creative in their communication and relationship patterns...and as losing their diagnoses'. Also, as stated previously, Lovaas (1987) described strategies for greatly improving language and social skills such that slightly less than half of the treated children achieve *normalcy*.

Based on the above arguments, Jordan and Jones (1995) and Schopler *et al* (1980) would seem not to hold views in line with the current thinking in the field of autism treatment. Further, Sallows and Graupner (1999) report that from their two years of data,

which includes testing by psychologists unaffiliated to their research: the London Early Autism Project, show preliminary indication of replicating Lovaas' 1987 ABA treatment results. This is an important issue when evaluating and reviewing the outcomes of research before deciding which strategies to implement in Kuwait.

In contrast, it was not until 1963, that the government in Kuwait established new institutions for dealing with children with special educational needs. These institutions catered for disabled children, physically and mentally disabled children, children with learning difficulties, and those with auditory, visual or speech difficulties. Then, in 1990 some private schools were established dealing with many of the learning difficulties and special educational needs, and in 1995 the local authority, in association with a charitable organisation, built a new institution, the Kuwait Autism Centre for autistic children. However, the capacity of this centre is insufficient to cover all the autistic children of the country. This fact has given rise to further private schools being established, in order to relieve the pressure of the Kuwait Autism Centre. Despite these ambitious plans, the private schools for special needs children in Kuwait have insufficient qualified and experienced professionals to deal properly with children diagnosed with autism.

Another problem arose due to the high cost of managing, resourcing and staffing private schools when dealing with children with special educational needs. Thus, in 1999 Kuwait's parliament raised the problem of high cost, so the government agreed to pay 87 per cent of the cost of educating each autistic child, with the parents paying the remaining 13 per cent. Whilst this is most certainly a very good move forward, the Kuwaiti government has stated that only a top figure of £4,000 per year may be spent on each autistic child. This may be seen initially as a large sum. In practice, much more money

is needed to provide adequate resources and provide well qualified, experienced staff. This is why 98% of the parents in this study identified the need for more government monetary support to assist them in meeting the needs of their autistic family member.

Secondly, in the UK the Education Reform Act (ERA, 1988) emphasised provision for the individual special needs of each child; as stated, this was superseded by the 1996 Act. Children with identifiable problems are referred by the local health authority and their needs considered by all relevant professionals, in partnership with the parents, in order that they may benefit from mainstream education. The outcome achieved successful placement of children, raising standards in most schools. However, implementation of the ERA (1988) is more problematic for special needs children, such as autistic children with other handicaps, who require a wide variety of support and specialism. Similar legislation pertains to the USA, Europe, Australia, New Zealand and other more advanced countries.

In Kuwaiti schools, the management body responsible for supporting special educational needs consists of the managers, social workers, psychologists and health workers in a unit. Generally, the teachers in the classrooms will identify the special needs of their pupils and send their findings to the social worker to follow through with standardised tests, after which the social worker may then refer the autistic children to a specialist for further examination. After these assessments, the professionals make a report to the school about the problem, showing the abilities and the special needs of that particular child. On receipt of this report, the school informs the parents about their findings. After a series of discussions with the parents, suggestions are made as to which institution can best support their child. Visits are sometimes arranged for the parents to

have the opportunity to assess the premises, the resources and the curriculum before making any decisions as to whether their child will attend.

As stated in the review of literature, in more developed countries much research has been conducted into the behaviour of autistic children and what the significant impact of their behaviour is on the families. Stress is reported to be one of the most frequent impacts observed. This study supports these findings. Since autism is one of the most complex and intractable developmental disorders which families may have to cope with (Howlin and Rutter, 1987), more research is required to understand and help families. For example, they found that the majority of parents shared very mixed feelings. Some reported stunned disbelief, others reported deep depression and sadness upon learning that their child was autistic. Similar feelings were expressed by the parents of the cohort in this study. The results of this study's findings share the acknowledgement that the degree of stress varies between the parents because of the abnormal behaviour of the autistic child, such as temper tantrums in public places; inability to socialise with friends and other kinds of challenging behaviour. Such behaviours, when researched, were found to put greater stress on mothers. Moreover, the biggest stress factor to parents was found to be the child's inability to communicate (Bristol and Schopler 1984; Schopler and Mesibov, 1985). Hence, the reason cited in the review of literature that when parents are asked to prioritise their preferences for intervention programmes, inevitably language, social and relationship skills are of prime importance to them.

In addition to this, the parents who opted to have their autistic children educated in residential establishments suffered significantly higher levels of stress compared with parents whose children attended ordinary schools. This was primarily found to be related

to strong feelings of guilt and shame. In Kuwait, although there is a lack of residential care, parents reported many feelings of guilt and failure. This was primarily because they could not access sufficient information and gain effective support. Most reported that they simply managed on a day to day basis with the support of their immediate and extended family. Thus, the stress factor can have severe consequences on the parents of autistic children.

Piven (1996) found that parents' suffering can be characterised by lack of interest in interaction with friends and families who may have an inability to appreciate the social-emotional behaviour of others. Further, social isolation and family disruption (Marcus, 1977 and Wahler, 1980), were cited as frequent factors which occurred as a result of stress related to abnormal behaviour of autistic children. However, it would appear that in Kuwaiti society the effect of stress upon families who have autistic children is less severe than the reported effects on western families. Although as stated above many parents reported their sense of failure, guilt, frustrations primarily due to lack of clear concise information and awareness of the support agencies.

This less severe effect of stress upon families may be due to the social and religious background of an Islamic society. As stated earlier in this thesis, the Koran places responsibilities on the extended family as well as the immediate community. These responsibilities are defined as caring for one another, thereby ensuring that much support and effort is given to families with disabled members. Because the financial and time-consuming burdens are divided among many more persons, the parents are able to have some rest from their autistic child. Such rest is twofold: (a) knowing their child is being well looked after, and (b) knowing that if they are short of food, money or clothing,

either members of the extended family or members of their immediate community will help. This difference in culture is important when assessing stress in parents and in the families of autistic children in an Islamic country and a non-Islamic country.

There is some funding available in the west to families of autistic children, e.g. for portage schemes and respite care. In addition, some parents in the UK qualify for an attendance allowance from the Department of Social Security, and Social Welfare in the USA. There are also resources available run by the National Autistic Society in the UK and in the USA. These include not only private schools for autistic children, but also support and information for parents. Some agencies encourage self-support groups to form in order to discuss and share experiences. Again, there are similar support resources available in the other countries cited.

In general, in Kuwait, provision for special educational needs is usually free, allowing children with autism to attend the Kuwait Autism Centre. However, because of the high demand for places in that centre, parents tend to register their children in private schools. They then have to pay 13 per cent of the yearly fee as discussed previously. Financial help for the low-income families is also available from the Department of Welfare. Equally, the Kuwaiti Government provides a free health care and health services.

The impact of the fact that the diagnosis process of autistic children in Kuwait, is difficult and time consuming, since each autistic child is different in many ways from other children with the same diagnosis, is now considered. Children who display abnormal behaviour will be referred to the doctor for diagnosis and he will consider

information about the child's past history and behaviour and assess to what extent this fits the pattern of early childhood autism. He should then investigate the possibility that the child has any of a number of conditions, which could be mistaken for autism, in particular that the child is not deaf, or visually impaired. The next step is to consider whether the child has any associate handicaps. These might be the abnormalities of the brain and nervous system, such as spasticity or fits, or he/she might have some other physical problems, which adds to his/her difficulties. Doctors have to be careful in assessing these extra handicaps, because the child cannot explain for him/herself. Further, his/her odd behaviour might hide symptoms and signs that would be obvious in a normal child.

The methods of diagnosis and the problems in Kuwait are similar to the west except that diagnosis takes much longer, because of the lack of qualified doctors and staff and shortage of medical facilities. As stated earlier in the thesis, hospitals and medical services are centralised as opposed to being located in communities. This entails some families having to travel long distances to obtain medical care if they do not live in the capital city, Kuwait.

The cultural and religious background has not much effect on the raising or the upbringing of autistic children of the west in comparison with the effect in Kuwait. In Kuwait, the cultural and the religious background has significant impact on the upbringing and raising of all children, and in particular autistic children. As stated previously, the majority of people in Kuwait are very religious and believe that autistic children are the creation of God and therefore everyone must care for them by looking after them in a way that satisfies religious principles. The Islamic belief is that if these duties are fulfilled, God will reward not only the parent of the autistic child at the end of their life, but also anyone who has helped and supported them. (This belief is not simply

for autistic children. Islam teaches responsibility for one's neighbour, whether he or she is disabled or not).

In the west, family members of autistic children suffer from disharmony or breakdown of relationships, due to factors such as stress, related to constantly dealing with abnormal behaviour. These families need the help and support of their relatives and their communities. Usually, training and individual therapy for group members of the autistic child enables them to control and handle their own mood swings and mixed responses. In general, western families do not share their problems with relatives, and even if they do, there will be very little contact, due to social isolation imposed by modern civilisation. In comparison, the social relationships in Kuwait between families and their extended family are very strong. Therefore, the families of autistic children receive support and help from their extended family. For instance, the families meet each other every week as a tradition to share their own problems and to find solutions, in which help and support can be offered. Nevertheless, parental responses showed that mothers, especially, would like opportunities to meet and discuss their problems with other mothers of autistic children.

Also, in the west, parents of autistic children have to face problems and stresses which are associated with the upbringing of their children every day. For instance, challenging the parents is the persistent demanding behaviour, frequent mood swings and short attention spans; frequent outbursts of uncontrollable frustration and anger, destroying their own toys or work and that of siblings. Also, at times autistic children have been reported as physically attacking parents, siblings or other family members. Further, it is required that the parent acts as qualified therapist for children by building speech and language skills; sustaining acceptable shaping of behaviours and act as the supervisor as a result of behavioural excesses (Kazdin 1980). The families in Kuwait experience similar repeated stresses to those in western families, but the impact of stress

on the Kuwaiti families is less severe for the cultural and religious reasons already cited. So, it is concluded that whilst there is significantly higher immediate and extended family support, parents still suffer from stress and stress related problems due to the impact of the behaviours of their autistic family member.

On the whole, people in the west, outside the family of autistic children, distance themselves from the impact of the abnormal behaviour of the autistic child and his family (Baker, 1988), whereas in Kuwait the culture and tradition act as one family. Therefore, the families of children with special educational needs receive help and support from their community much more than those in western families.

Similarities

1. In both the west and Kuwait, there are private schools and government institutions dealing with special educational needs.

2. In Kuwait and the west there is funding available to low income families of disabled children and therefore autistic children.

3. The methods of diagnosis in Kuwait and the west are similar, but in Kuwait the process is much more time consuming because of lack of medical centres and qualified medical staff.

Dissimilarities

1. In Kuwait the private school and government establishments lack qualified professionals to deal with autism.

2. The degree of the impact of stress upon the parents of autistic children in Kuwait is less severe in comparison with the west, due to cultural and religious

factors, whereby families receive extra help and support from relatives and communities.

8.2.5 Criticism of parental questionnaires

Rutter and Schopler (1987) voiced their criticism of a parental questionnaire as it cannot satisfactorily tap the distinctions on the quality of behaviours needed for diagnosis. They stated 'The instruments based on observation are potentially more satisfactory, but they are necessarily limited to the behaviours likely to be manifest during a relatively brief period in a single setting' (ibid., p. 53ff). It is acknowledged that whilst parents may not be professional assessors, they know their children better than other people, and therefore, have a good overview of abilities and development. It is acknowledged that they may also possibly be prone to more subjective distortions of data due to their emotional involvement. The researcher found that although some parents tended habitually to over-estimate, whilst others under-estimated their child's level of competence. Newsom (1976, p. 4) endorses this type of information gathering, when stating 'We start from the basic assumption....that parents are experts on their own children. This is not to say that they know of their children in any systematic or integrated form:...Nonetheless, they know more about the child, on a very intimate level, than anyone else does;...I find it extraordinary that the resource of parents as an information stores is so often neglected...'.

8.3. Summary of the Chapter

This study has attempted to discuss the findings of this study by assessing the impact of children with autistic behaviour on their families in Kuwait, in the light of current thinking world-wide.

In an attempt to clarify what is meant by autism, Kanner's (1943) original description and subsequent diagnostic and criteria were viewed. It was seen that there has been a shift in thinking as regards aetiology, from psychogenic theories, towards a biological stance, though research also supports the effectiveness of behavioural approaches to treatment.

The key elements of autism are impairments in social relationships, social communication, and social understanding and imagination. These give rise to a range of characteristic behaviours including self-estimation, SIB, obsessive demand for sameness and distinctive speech characteristics. A highly uneven profile in a range of functioning areas is exhibited. The behavioural model of treatment, while it does not provide a cure, has proved useful in controlling the inappropriate behaviours which so badly impede the social functioning of autistic children.

It has been shown that in the UK and USA, education and management involves the combined efforts of clinicians, parents, teachers and therapists. A range of provision is available to meet the special educational needs of autistic children, and various sources

of community support and information exist (notably, the relevant National Societies), and extensive research is being conducted.

In Kuwait, the position is somewhat different, as it is only recently that autism has been fully recognised as a distinct category of disorder, and little specific exists. Various government and private bodies organise and finance provision, and charitable donations play a significant role. Such provision as does exist, appears to be in line with current thinking in terms of its multi-disciplinary approach, individually-tailored programmes, and recognition of the importance of providing information and developing public awareness. However, provision is confined to one or two urban centres, and it seems probable that only a small proportion of the autistic children (number unknown) in the country are able to benefit from it at present. Moreover, information is still limited and public awareness of the problem is low. This chapter has laid the platform for the next chapter where recommendations and future research are detailed.

Chapter Nine
RECOMMENDATIONS AND CONCLUSIONS

9.1 Introduction

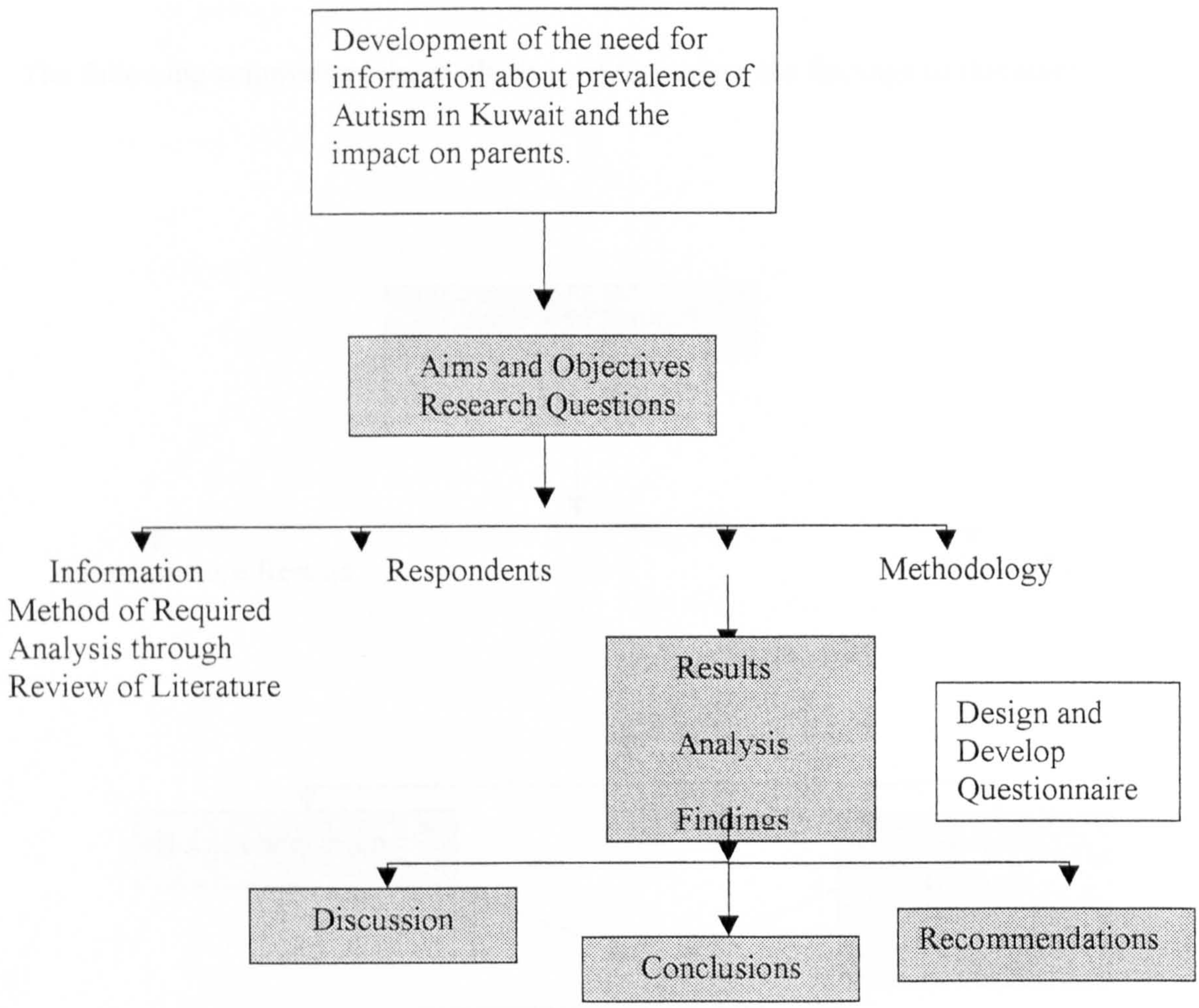
Having detailed the results of the questionnaire collecting data related to families' responses to an autistic family member, the researcher will in this chapter offer some recommendations, both for the development of provision for autistic children in Kuwait, and for further research.

9.2 Summary of the Research

The following is a diagrammatical presentation of the way in which this study was designed and executed. It states the problem that this study attempts to address, followed by the methodology to design and develop a questionnaire to be used to obtain the information. After this the results of the findings were analysed, discussed from these conclusions and recommendations were made.

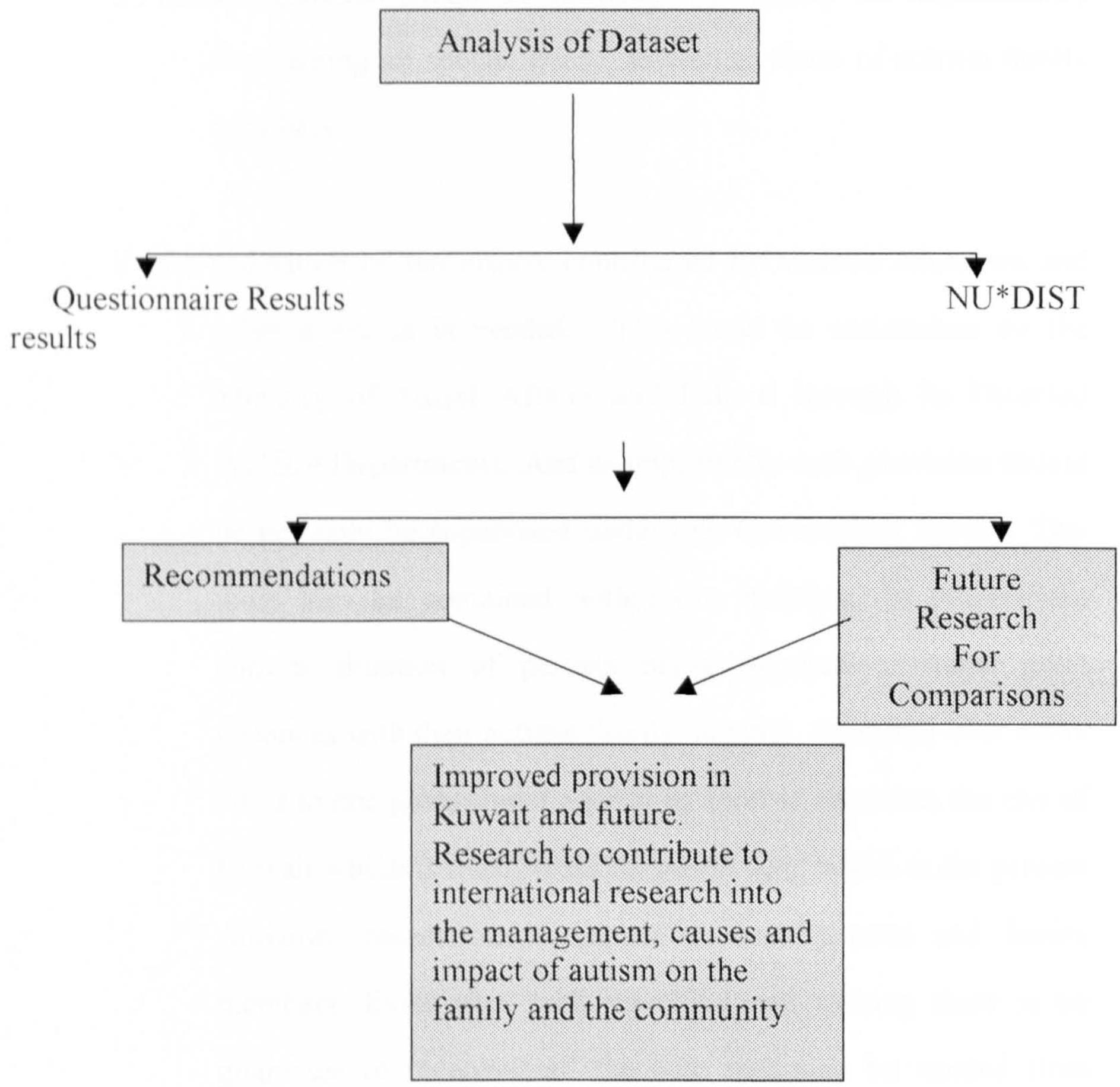
It was found that there were some parallels to existing literature on the way in which an autistic family member's challenging behaviour impacts on the family as a whole, and specifically on the parents. However, because of differences of culture and traditions it was found that the Islamic way of life contributed to differences in results. Equally, both pilot study and main study findings demonstrated that because of strong family loyalties their responses were not as diverse as those in the review of the literature. The researcher, therefore, suggested that further research would need to be done into comparing Moslem families all over the world. And in a variety of cultures to ascertain if the findings of this study could be generalised to all Moslem cultures.

Summary of the Research diagrammatically.



9.3 Summary of the methods used to analyse the Findings

The following summarises the methods used to analyse the findings of this study.



9.4 Recommendations

The following suggestions are made to clarify and improve the situation with regard to provision for autistic children in Kuwait.

i. Precise legislation should be formulated to clarify the responsibility for meeting all special needs, as well as those of autistic family members.

ii Co-ordination of the efforts contributed by various ministries and other agencies is needed. This could be undertaken by the Ministry of Social Affairs and Labour through its Disabled Welfare Departments. And as importantly such provision should be not only be supervised under one Government agency. This must also be contained within one building, to prevent the current situation of parents being required to travel great distances with their autistic family member. As stated after many visits to one government agency to another all across the city of Kuwait which is over 30 kilometres in size, which is the present situation, causes much distress to both parents and family members. Even after such travelling and visiting there is no guarantee of receiving all the help that may be needed from these agencies. With having everything associated with the provision of support and guidance in one building this would help enormously.

iii Introduction of a systematic procedure for identification and referral of special needs would be beneficial. This would standardise the present procedures and ensure that all cases of reported autism

are in fact autism and not other similar symptom disorders. Computerisation of such procedures would be very advantageous as well as being easily accessible to all involved in the support of family members with autism.

iv. To make possible the extension of the provision currently available, attention needs to be paid to the training of more specialists (doctors, teachers, therapists) to deal with autism. This is seen as essential in order to bring the provision and support for autistic family members level to those received by autistic people in the UK, USA, Europe, Australia, New Zealand etc.

v. The Kuwaiti government through the provision of specific grants and funding into the causes, effects, provision and support of autism, and the Kuwait University should encourage further research into the causes, treatment and management of autism.

vi. The establishment of a National Kuwait Autistic Society (which could operate as a charity: government grants might also be made available) is desirable. Such a society, like its Western and Australasian counterparts, could provide advice and information to parents and teachers, stimulate research, and help to promote understanding and awareness of the disorder among the general public.

vii. The mass media (particularly radio and television) could play an important role in increasing public awareness of special needs, through documentaries and public service broadcasting. This would help to lower the stigma of having a disabled child.

Related to ways in which parents specifically could be assisted to make informed decisions after receiving confirmation of a diagnosis of autism for a family member, the following are suggested processes and some issues for consideration in deciding best ways to help the autistic family member become self reliant in Kuwait. The starting point is primarily intended for a parent with a newly diagnosed family member, as some parents may have received support or been given experiences of the following.

9.4.1 Home Based Programmes

9.4.1.1 Intervention 1: Behavioural Intervention (ABA) 'Lovaas method'

As stated above, in the previous Chapters Two and Three parental involvement is crucial for a home based programme to be successful as it is recommends that families work with their child for thirty five to forty hours per week. This is a very heavy time commitment. Thus, most parents in the UK or the USA, are either a member of the team and work with the child for some of the hours each week or attend weekly team meetings and are mainly responsible for generalising tasks outside work hours. With the close family and immediate community ties within the Islamic society, this could be more easily implemented, should the Lovaas method be adopted as a national programme in Kuwait provided that caution is taken as described in Chapter Four. Again, as stated in Chapter Two caution and heed must be taken to the on-going debate related to which programme is the more effective. However, the researcher believes that a selection of programmes must be available for parents and professionals to use within the context of an Islamic culture, and for them to find for themselves which or a combination of some programmes best meets the individual needs of the autistic family member.

This recommendation of the ABA (Lovaas method) is based on the following evaluation points:

- Early intervention: This approach works with young children, although recent works by Eikeseth *et al* (1999) suggests that it is equally effective with others. Whilst autistic family members would be the prime receivers, other family members with a range of disabilities could also gain from this approach. Such versatility has much to recommend it given the financial considerations, as well as meeting the needs of all citizens of Kuwait regardless of their disabilities.

- Intensity: One to one intervention for a length of time, averaging 25 to 40 hours a week, is very demanding. But again with close Islamic family and community ties, this could be made possible and, more importantly sustainable over a long period of time. Because of this it would be practicable as well as being effective if the criterion for success is length of time spent implementing the procedures.

- Research: Based on publications, such as Lovaas (1987) and McEachine *et al* (1993), several sites around the world (one is at Brunel University in London, sponsored by PEACH) are replicating his research. PEACH estimates that currently there are 71 LEAs in the UK funding home based behavioural programmes (cf. SPEECH, September 1999). However, in most cases parents need to start the programme themselves,

and petition the LEA for funding. This can be a long process and often parents are initially self-funding. However, if implemented in Kuwait, perhaps government funding could be specifically identified for an on going programme to ensure continuation and sustaining of advances made by autistic children. And again, by establishing a site in Kuwait, international research could be undertaken along with continuous monitoring to evaluate the effectiveness and to identify where changes and improvements could be made to meet the specific needs of the culture and traditions of Kuwaiti citizens.

9.4.1.2 Intervention 2: Options

As cited above, the *Options* approach was developed by Barry and Samahria Kaufman, based on the personal experiences with their son Raun, who is severely affected by autism. Whilst there have been no controlled investigations and research results into this form of treatment, which is a distinct disadvantage regarding demonstrating well founded bases and good practice, the researcher would still recommend implementation in Kuwait based on the following evaluation points of Options:

- Early Intervention: As a home based programme it is for young children, but claims to help all ages. For similar reasons given above, Islamic culture and religion could sustain the implementation of such a programme.

- Intensity: The Kaufmans worked with their son seven days a week, twelve hours a day. So, the actual number of hours a family works

would be an individual decision. Again, whilst extremely demanding it would not be impossible to organise and sustain this programme with the support of the immediate Islamic family and immediate community.

- Research: Anecdotal parental comments have been used, but no structured research has been published to-date. This is seen as a weakness but with the establishment of international research and a centre for excellence related to research into autism in Kuwait, hard data could be generated, thereby positively contributing to the existing research into autism and the effectiveness or not of such a programme.

- Generalisation: Initially the child is kept in an environment away from the outside world. Gradually the child is supported in his/her efforts to enter a larger environment. As stated above, this would be possible within the extended Islamic family setting within Kuwait.

9.4.2 School Based Programmes

9.4.2.1 Intervention 3: TEACCH

As detailed in Chapter Two, Treatment and Education of Autistic and related Communications Disabled Children (TEACCH) is based largely on the work of Dr. Eric Schopler, within the state of North Carolina, USA. He developed the method of using a visual approach in structured teaching situations with autistic children. Despite the on-going debate outlined in Chapter Two, if such a method could be introduced into a national programme within Kuwait, this could provide an essential element of double

support: [a] concentrated efforts in school followed by [b] appropriate support from the family.

The researcher would recommend implementation of the TEACCH method in Kuwait based on the following evaluation points:

- Early intervention: As a school based programme it is not specifically targeted for young children but for individuals of all ages. So again it would be of possible support to other children who were not diagnosed as being autistic.

- Intensity: Variable, dependent on the classroom or parent input and ability to sustain their efforts. Also, the extended family would be able to give support to the recommendations and the wishes of the school so it is possible to implement this programme with the joint support of family and school.

- Parents: Parents are encouraged to use the techniques at home, but it is not essential. This would be possible given the Islamic religion and traditional family and extended community support cited above. Also, it may be possible to establish a parents' self help group where discussions and exchanges of ideas could be made. This would help to identify common problems and issues of concern.

- Research: As stated according to Jordan *et al* (1998, p. 88) 'although TEACCH is one of the longest established programmes with an international influence although there has been surprisingly little done to evaluate the programme in terms of outcomes'. So if a centre for excellence in research were established in Kuwait, this could be used as part of the evaluation of the TEACCH programme, plus other programmes, to provide valuable data for comparisons and inform future government and medical policy decisions. Not only would this be useful in Kuwait allowing parents to decide which programme is most effective with their own child, but Kuwait could then contribute to the international research on autism.

- Generalisation: The results vary as it is greatly dependent on those individual adults working with the child. Because of such variations much could be standardised with the co-operation and help of the Islamic extended family and community to ensure equity for each autistic family member. This could be through self-help groups, as well as through the controlled experimental monitoring and evaluation systems in place. Again, this would provide hard data, which could possibly contribute to worldwide understanding and support for autistic family members.

9.4.2.2 Intervention 4: PECS

As stated previously Picture Exchange Communications System (PECS) was developed by Frost and Bond (1994) as a means of helping special needs children

communicate. Although it has not been evaluated in comparison to other programmes, according to Jordan *et al* (1998) it appears to yield gains in the child's ability to communicate, even among those with severe limitations. The researcher, therefore, would recommend implementation in Kuwait based on the following evaluation points of PECS:

- Early intervention: Although developed as a school based method in the USA, it can be used with individuals of all ages as the early it is used as an intervention programme to assist in helping special needs children to communicate the better. Thus, after being established and after ensuring its effectiveness in Kuwaiti schools, it would be developed into a family orientated programme, or a joint school and family programme. This way the child would be given consistent and sustainable experiences of one specific form of communication.

- Intensity: Ideally, this should be used each time the child wishes to communicate for the reasons given in the previous bullet point. Home and school support and co-operation could very easily be established to achieve this aim in Kuwait for the reasons described above.

- Parents: Parents are strongly encouraged to use this technique whenever their child wishes to communicate. As cited above the close family ties and community ties could ensure that there is

consistency in approach to the autistic member, thereby, establishing stimulus/response behaviour patterns. Also, with lots of practice, which is consistent, the family member should improve more effectively than if exposed to various methods.

- Research: Three studies showing the outcomes of the Delaware Autistic programme were conducted by Frost and Bondy (cf. Bondy *et al.*, 1994). These concluded that children made gains both in using PECS and in spoken language acquisition. So with the establishment of research within Kuwait this could contribute and possibly inform international findings. It would certainly be able to generate hard data related to Islamic family use of such a programme. This could be compared and contrasted with non-Islamic results, as well as compared and contrasted with other Islamic countries' findings. Thus, there would be an enriching of research findings.

- Generalisation: There is potential to use this method in most of the child's environments in Kuwait. Parents are encouraged to participate. As cited above, given the traditional cultural and religious Islamic support for each member of the family, it would not be difficult to establish patterns of behaviour using this method, and these could be sustained and consistent in approach by the whole community for the good of the autistic family member.

As stated in the text of this study and in conclusion to the above, the researcher totally agrees with the following and strongly recommends its application to the current situation in Kuwait:

> 'Intervention in early childhood can have a major impact on the quality of life in adulthood and is likely to prove far more cost effective than crisis management in later life'
>
> (Howlin, 1997a p. 69).

Supporting this statement, Fenske *et al* (1985) and the National Autistic Society - UK (1997) advocate that a structured approach to helping a child should begin as soon as possible after realising there is a problem with the child. Early intervention is of the essence if everything possible for the autistic family member is to be achieved to allow him/her to meet his/her full potential.

9.5 Suggestions for Further Research

Understanding of autism in Kuwait is in its infancy, and research in a number of areas, is needed in addition to areas for further research already identified in the body of this study.

i. No accurate statistics exist regarding the incidence of the disorder in Kuwait. Research is needed to investigate the scale of the problem, so that sufficient special provision can be planned and a variety of programmes of intervention can be assessed, evaluated and implemented.

ii. It would be helpful to conduct research into attitudes to disability in Kuwait, and to see the effect these may have on the availability of special provision and support.

iii. Research should be conducted in the new Autism Centre and other institutions dealing with autistic children, to follow up children's progress and evaluate the effectiveness of treatment and management approaches. Likewise, the training programme for support workers, teachers and counsellors associated with autistic children would be monitored and improved over a period of time. This would ensure effective use of funding, time and expertise to support the families of autistic children.

iv. Research needs to be conducted to explore differences which might exist in maternal and paternal perceptions, to ascertain if any differences do, in fact, exist. As the Islamic culture is that the man is the head of the family, there could be inferences of this related to autistic family members' support and provision of various services. How these are obtained and sustained will depend very much on the father as well as the mother, although the mother will have the most to do with the child initially.

v. Further, because of the change in needs, and support according to the age of the family member, research could be designed to investigate differences in helpful resources and severity of challenging behaviours, across all age groups. This would possibly identify the change in needs for support and availability of specific needs according to preschool, primary, adolescent and adult age groups.

vi. Because some families appear to cope far better than others with autistic family members, there is a possibility of collecting information to identify the characteristics of successful families by delineating their strategies in order that they can be adopted by other less successful families. Also, this could contribute towards Kuwaiti knowledge of the ways in which families deal with and are affected by having an autistic family member.

vii. Programmes need to be developed to disseminate and enhance the family's abilities to develop their own coping strategies and sustain them over long periods of time. So self-help groups, charities, government organisations and agencies need to address the general issue of educating Kuwaiti citizens about their disabled members. And offer advice on which would be the more effective ways of supporting and providing help within the family as well as the community.

viii. Because of the on-going debate into which is the most effective intervention programme Kuwait could possible play an important part in contributing to the existing data through research into the effectiveness of each programme, and/or research into a combination of aspects from each programme which are identified to be effective within an Islamic culture. This is all the more important as the understanding and management of autism in Kuwait is in its infancy, and therefore, allows for more flexibility in experimentation and approach than maybe the case in countries who have an established history of provision for autistic family members.

9.6 Weaknesses in this study

As stated previously, due to the lack of statistical information related to the incidences of standardised diagnosed autistic family members, it has been difficult to ensure that all of this sample was in fact truly autistic. Or, that the 52 respondents are truly representative of the autistic population in Kuwait. Thus, caution must be taken when considering the results of the findings, because obviously the results will be weakened if not all of the sample is truly autistic and representative of the total autistic population in Kuwait.

Further, with hindsight, it would have been preferable for full interviews to have been designed and to be undertaken separately from the questionnaire completion interview. This could have resulted in two sets of data being generated. Also, better comparisons could have been made between what each respondent perceived verbally and what they recorded as their answer in the questionnaire. A properly designed and conducted audio taped interview aspect to this study would have allowed for a fuller analysis of raw data using qualitative software packages such as NU*DIST, as much of the conversation audio taped in this study was informal and specifically related to ensuring clarification of understanding of the questions being asked.

Originally, the researcher's intention was not to analyse these audio taped conversations, but simply to listen carefully to them to ensure that respondents had clearly understood the questions, and that the researcher had not intentionally or unintentionally influenced the answers given by the respondents. However, as stated above, after listening a few times to the audio tapes, the researcher decided that whilst much caution must be taken when generalising the NU*DIST results, there was material and data of value in them.

This *ad hoc* type of analysis is obviously a weakness, although it did give significant and clear indications that some respondents were attempting to ensure that they gave the *right answer* to the question, and not as was intended in the questionnaire design, giving a true perception of their beliefs and experiences. The audio tapes highlighted the need for stricter research design, with a developed and an agreed protocol of interview procedures between the researcher and an independent observer. With the addition of video recording of the whole interview, the independent observer could then watch a video recording of the procedures used by the researcher to ensure that there was no research bias. Also, this would allow for better analysis of instances where the husband, as the head of the family, dictated what the answer was to specific questions.

Because of these cultural differences between the western world and Kuwait, the researcher felt that had mothers been interviewed on their own, different answers may have been offered. It is important for the reader to be informed that this is strictly forbidden in Islam. No man is permitted to be alone with a woman. Because of this a female interviewer would need to be employed if such research were to be conducted. Therefore, in this present study it was impossible for this type of interviewing to take place without the presence of the husband or a male family member. Thus, whilst adhering to religious rules, this study was weakened by this religious ruling. Family loyalties are extremely strong in Islam, the principal religion of Kuwait, and therefore, neither male or female family members will publicly speak against or give a different answer from that offered by the head of the family.

As the fact that more than one person would be conducting aspects of the study if it was decided to employ a female to interview the mothers, this would mean that strict protocols and adherence to agreed procedures would have to be in the research design to ensure consistency of approach, as well as controlling for research bias.

9.7 Summary of the Chapter

This chapter has outlined the recommendations from the research findings.

In conclusion, it is hoped that this study will contribute in some measure to the emerging understanding of autism in Kuwait, and that implementation of some of the recommendations made here would maximise the effectiveness of the recent efforts to cater for the needs of autistic children and their families. It is further hoped that this study has identified areas for future research which will contribute to the international arena in the understanding and management of autism.

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http://www.info.med.yale.edu/childstudy/autism

http://www.udel.edu/bkirby/asperger

http://www.autism-society.org

http://www.QSR.com.au

Appendices

Appendix A

Diagnostic criteria for autistic disorder from DSM-IV

At least 8 of the following 16 items are present, these to include at least two items from A, one from B, and one from C.

Note: Consider a criterion to be met only if the behaviour is abnormal for the person's developmental level.

A. Qualitative impairment in reciprocal social interaction as manifested by the following:

(The examples within parentheses are arranged so that those first mentioned are more likely to apply to younger or more disabled, and the later ones, to older or less disabled, persons with this disorder.)

1. marked lack of awareness of the existence or feelings of others (e.g. treats a person as if he or she were a piece of furniture; does not notice another person's distress; apparentiy has no concept of the need of others for privacy)

2. no or abnormal seeking of comfort at times of distress (e.g. does not come for comfort even when ill, hurt, or tired; seeks comfort in a stereotyped way, e.g. says "cheese, cheese, cheese" whenever hurt)

3. no or impaired imitation (e.g. does not wave bye-bye; does not copy mother's domestic activities; mechanical imitation of other's actions out of context)

4. no or abnormal social play (e.g. does not actively participate in simple games; prefers solitary play activities; involves other children in play only as "mechanical aids")

5. gross impairment in ability to make peer friendships (e.g. no interest in making peer friendships; despite interest in making friends, demonstrates lack of understanding of conventions of social interaction, for example, reads phone book to uninterested peer)

B. Qualitative impairment in verbal and nonverbal communication, and in imaginative activity, as manifested by the following:

(The numbered items are arranged so that those first listed are more likely to apply to younger or more disabled, and the later ones, to older or less disabled, persons with this disorder.)

1. no mode of communication, such as communicative babbling, facial expression, gesture, mime, or spoken language

2. markedly abnormal nonverbal communication, as in the use of eye-to-eye gaze, facial expression, body posture, or gestures to initiate or modulate social interaction (e.g. does not anticipate being held, stiffens when held, does not look at the person or smile when making a social approach, does not greet parents or visitors, has a fixed stare in social situations)

3. absence of imaginative activity such as playacting of adult roles, fantasy characters, or animals; lack of interest in stories about imaginary events

4. marked abnormalities in the production of speech, including volume, pitch.

Appendix B

The Code of Practice from the Education Act 1996 – United Kingdom.

This Act obligates governing bodies to have regard to the Code of Practice when carrying out their duties towards pupils with special educational needs in the UK.

Stage 1

This involves 'taking early action to meet the child's needs within his or her normal classroom work and monitoring and reviewing his or her progress.

Stage 2

At this stage 'the SENCO (SPEcial Educational Needs Co-ordinator) takes the lead in co-ordinating the child's special educational provision, consulting the child's teachers, who remain responsible for working with the child in the classroom. The SENCO, working closely with the child's teachers, ensures that an individual education plan (IEP) is drawn up.

Stage 3

The responsibility at this stage for the child's needs is shared with an external specialist, who may offer advice, assessment or direct intervention. The external specialists may include clinical and educational psychologists, specialist teachers, speech and language therapists and psychiatrists. The provision could be a mixture of in-class support and small group teaching, or in-class support and individual teaching.

Stage 4

'The needs of the great majority of children who have special educational needs, should be met effectively under the three school-based stages, without the statutory involvement of the local education authority. But in a minority of cases, perhaps two per cent of children, the LEA will need to make a statutory assessment of special educational needs. Statutory assessment is the focus of Stage 4 of the five-stage model.'

Stage 5

This final stage involves the issuing of a Statement of Special Educational Needs, which carries with it certain legal responsibilities that cover funding, resources, and an annual review of the child's progress. LEAs are obliged to complete the process of statutory assessment within a given period of time. (Cited in Aarons and Gittens 1999, p. 78).