IRISH FAMILIES UNDER STRESS

PLANNING FOR THE FUTURE OF AUTISTIC PERSONS

A Prevalence and Psychosocial Study in the Eastern Regional Health Authority (formally The Eastern Health Board) Area of Dublin

VOLUME 6

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Reprinted 2000

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Preface

I am very glad to see that Professor Fitzgerald is continuing to carry out research on Irish families under stress. It is important that the causes and effects of stress on families continues to be researched, and that the outcomes of that research are published as in instrument for planners, including health planners, at national and local level.

The challenges and demands placed on families in the 90's are varied and take on a totally different dimension when a family unit has cared for a member who is elderly or disabled. In this regard a family member with autism presents a particular challenge. The support provided by the health services, with a range of programmes of day care, home support, educational, and respite, is very much welcomed by the parents and siblings of the autistic child. Cognisance has to be taken of the care demand met by the family unit. Professor Fitzgerald's research on the stress associated with family care will be welcomed by those families and health care providers generally.

Michael Walsh.

Foreword

Michael Fitzgerald who fills the first Chair of Child & Adolescent Psychiatry to be established in the Republic of Ireland, more than justifies, not only the establishment of such a Chair and department, but also his appointment to it. We all should be thankful that a person with such an open and actively enquiring mind, possessing of so much dynamic energy, should arrive on the scene at this moment in the evolution of Ireland's health and social services.

Professor Fitzgerald has contributed an enormous amount of scientifically important and valid research (particularly in the epidemiological field) over many years. In this collection he continues his invaluable documentation of the conditions of children and families in Ireland. He has maintained his steady build-up, not only of the significantly important data on the prevalence of childhood disorders, but also of the environmental settings in which childhood experiences are embedded.

In his comprehensive survey of childhood autism (and indeed young adulthood) in the South Western Area Health Board region, he used such well validated instruments as the "Autistic Disorder Diagnostic Checklist" (ADDC), the "Vineland Social Maturity Scale" and others. He makes us aware of the fact that there are in the region of 270 persons in the age group 0 to 25 years disabled by autism. His findings present us with, both a quantitative and qualitative appreciation of the practical issues with which families and services have to contend. This is altogether a most useful collection of data for service planners to have available.

Of the information coming from the many other studies whose findings he summarises, perhaps the most striking is the prevalence of current clinical depression (40%) in the

mothers of children presenting to child psychiatric clinics, and the extent of serious financial and relationship problems in such families. The studies quoted cover a wide and varied range of psychiatric disorders presented by children in the community child psychiatric clinics. They range from eating disorders to fire setting, anxiety disorders, to depression and psychoses.

His comment that disadvantaged areas are "increasingly psychologically toxic to families and children" is perhaps something we would have assumed, but to have it documented so clearly has almost frightening impact. The facts he presents should give support to those in Government who would seek imaginatively to improve the circumstances of disadvantaged families.

Dr. Paul McCarthy,
Clinical Director.

The Irish Society for Autism

History

The Irish Society for Autistic Children (I.S.A.C.) was founded in 1963 and was renamed The Irish Society for Autism (ISA) in 1992. After its foundation I.S.A.C. realised that the initial enthusiasm of professionalism and statutory bodies very quickly subsided and then failed to provide the specialised services required by children with autism. The long campaign began, a campaign of education and creating awareness, insisting on the need for early diagnosis, early intervention and above all appropriate education. While this campaign was in motion the Society in partnership with the Eastern Health Board set about developing services for young adults with autism who unfortunately were at that time in totally unsuitable psychiatric hospitals. The Gheel Training Group was formed and now provides day and residential facilities in the community care model for fifty-two persons with autism in the Dublin area.

For some time the Society had been aware of developments in the UK and France, where community based rural projects had been established and had proven very successful. In April 1981, nine members of the society, including parents, staff and two children with autism visited the La Bourguette farm complex near Aix en Province, in the South of France, and also Somerset Court, Longford Court and Anglesea Lodge in the UK. We were encouraged by the tremendous achievements observed in those places. A national television appeal on behalf of children with autism on a popular children programme "Youngline" raised the magnificent sum of £72,000. This enabled the Society to bid successfully for Dunfirth House and Farm, near Johnstown Bridge, in North County Kildare, approximately 25 miles from Dublin. The purchase was completed in July 1982. The farm had a residence and substantial outbuildings, together with approximately 70

acres of land and now forms the basis of the first development in Ireland of an integrated, rural based community for thirty-six persons with autism.

The Organisation

The headquarters of the ISA are situated in No. 16, Lower O'Connell Street, Dublin 1. All of its activities are co-ordinated from this office while include:

A Drop in Centre: A centre, complete with audio video equipment and access to many books, publications and videos where parents, professionals and students can meet to discuss autism and the problems faced by people with autism. Advice and support is always at hand.

Activity Management: All of the Society's fund-raising activities which include Golf Outings, Annual Gala Ball, Fashion Shows, Art Auction and other appeals including "Rose Week Campaign" are organised and co-ordinated from this office.

Seminars and Meetings: The ISA hold monthly Board Meetings in O'Connell Street and Meetings of the parents of younger and recently diagnosed children are held bi-monthly. An autism study weekend is held each year.

The ISA is very active in assisting and support Autism Europe (AE) in putting together the European Congresses. The Executive Director of the ISA is also the Vice-President of AE.

Public Relations: The ISA is very active politically and has enlisted the support of many well known politicians to pursue its aims. We always try to maximise on any happenings which might highlight autism or present autism to the public in a positive way.

During the past years Stephen Wiltshire, a British artist with autism, Donna Williams, Australian author of "Nobody Nowhere" and William Christopher, Fr. Mulcahy in MASH, who has a son with autism, have all visited Dublin and featured in the ISA's publicity programmes.

Research and the Years Ahead

As we become more knowledgeable about autism and adults with autism, there is a greater realisation that although people with autism can acquire, improve and develop their skills, they will continue to require intensive continuity of training to enable them to reach their true potential.

We know that given the right training and by creating meaningful work opportunities in a suitable environment our young people with autism can lead greatly enriched lives.

We need to be more research orientated if we are to fully understand this complex syndrome. Data collection and evaluation is one way which we can assess the needs of people with autism and respond accordingly.

It is the stated intention of the ISA to continue to initiate and be involved in all areas of research which could help to improve diagnosis, treatment, education and the quality of life for people with autism.

I congratulate and thank all who were involved and assisted us in this project.

P.D. Matthews
Executive Director ISA
Vice-President Autism Europe

Summary

Introduction

Kanner described autism in 1943 and stated that the condition he described "differs . . . markedly and uniquely from anything reported so far". He noted an inability to relate to people; mutism or abnormal, largely non-communicative use of language in those who did speak with pronoun reversal and echolalia; abnormal responses to environmental objects and events with an obsessive desire for maintenance of sameness. Kanner (1965) complained of two related trends in child psychiatry. On the one hand some child psychiatrists did not accept that autism was a distinctive syndrome while others applied the diagnosis too widely. While nobody denies the existence of autism today there is still debate about the boundaries of the condition. Gillberg (1992a) states that Kanner's description of autism has lead to "stagnation in thinking about autism". He states that "we have not been able to find any support in the literature for "Kanner's autism" being more valid than other variants of the "triad of social, communication and imagination impairments" (Wing, 1989). There is therefore a need to compare the results of different classification systems of autism with the same group of persons as has been done in this Eastern Region Health Authority (E.R.H.A.) study.

Clearly the prevalence of autism is going to be influenced by the criteria used to diagnose it and the methods of ascertainment. The early population based studies found a rate of about 4.0 / 10,000 (e.g. Lotter (1966) 4.5 / 10,000 in 8 - 10 year olds). More recent studies have shown a considerable increase in these figures. This increase has been considered in terms of changing diagnostic criteria, for example the broader criteria of DSM-III-R (APA, 1987); better ascertainment procedures; autism associated with immigrant status; identification of milder forms of autism; early diagnosis of autism in young pre-school children as well as increased diagnosis of autism in persons with severe mental retardation.

The effects on a family having a person with autism can be very considerable but nevertheless variable. While negative effects on the family are most common, positive effects can also occur. Social support for the family as well as spousal support within the marriage or partnership is important. The effect on siblings reported equally mixed outcomes. Coping patterns of families also vary with some evidence that "close-knit" families with an ability to adjust as the child's needs change being more successful.

Clearly all these factors have implications for services. Services can be helpful or cause increased stress for the family of the person with autism.

This E.R.H.A. study examines issues of diagnosis, prevalence as well as psychosocial and service issues in a population of 1.25 million people.

Methods

All centres in the E.R.H.A. area with children and adults up to 25 years with special needs were identified and contacted regarding the study (n = 25). All co-operated with the study. Initially the staff were asked to identify any person with an "autistic tendency" in the centre. This was followed by a discussion by one of the author's (M.F.) of all features of the Autistic Disorders-Diagnostic Checklist (Wing, 1987 - Personal Communication) with the staff. Each centre was then visited by experienced psychologists who carried out further detailed discussions with the staff on the features of autism and administered to the key workers the Autistic Disorders-Diagnostic Checklist and a Services Questionnaire.

The second phase of the study focussed on the 100 mothers of persons with autism who lived in the West Dublin and Kildare area of the Eastern Region Health Authority. All these were visited in their own homes and administered:

(1) The Social Questionnaire.

(2) The Family Burden Schedule.

(3) The General Health Questionnaire.

(4) The Parental Questionnaire.

(5) The Vineland Maladaptive Behaviour Domain.

(6) The Index of Social Competence.

Finally a control group of 30 mothers with children in normal schools were also interviewed in their homes.

Results

Prevalence of autism:	4.9 per 10,000 population 0 - 25 years. (Autistic Disorders Diagnostic Checklist / In contact with services).
Month and season of birth:	There were no significant differences between months and seasons of birth.
Birth order:	There was no significant differences between birth order and autism.
Siblings of persons with autism:	Thirty-two percent (32%) of persons with autism had two siblings and 22% had one sibling.

Sex differences in relation to individual items of the Autistic Disorder-Diagnostic Checklist:

1) "Abnormality in pitch, stress, rate, rhythm, or intonation" was significantly more frequent among female subjects.

2) "Lack of own awareness for need for personal modesty" was significantly more frequent among males.

Social competence of persons with autism: The majority of persons with autism had normal vision (96%) and hearing (90%). Poor communication skills were problematic with 76% only following simple instructions and only 12% being able to speak well and intelligible to all people. Almost one third (30%) had no speech or gesture.

The effect of having a person with autism in the family:

1) The extra expenditure incurred was a moderate burden for 41% and a severe burden for 38%.

2) The person with autism disrupting routine family activities was a moderate burden for 21% and a severe burden for 44%.

General Health Questionnaire:

Fifty eight mothers (58) scored below cut off of 5 while 34 scored at 5 or above (total n = 92) and showed evidence of psychological stress. Approximately a quarter of the mothers had problems concentrating (26%) while 19% said they were loosing confidence in making decisions. Thirty percent (30%) of mothers were "taking things hard". There was a significantly greater overall burden experienced by mothers scoring 5 or more on the G.H.Q. These mothers also experienced significantly more problems with their partners.

Impact on siblings:

There was a severe negative impact on 29% of siblings and no impact on 18%.

Residential status and age:

There was a significant positive correlation between residential status and age, as older subjects were more likely to be in residential care.

Conclusion

The staff's ability to identify persons with autism was reasonably good in that they successfully identified 272 out of 309 correctly on the Autistic Disorders Diagnostic Checklist. As regards ICD10 draft research criteria 144 out of 309 met these criteria. As regards Kanner's 5 criteria 24 out of 309 met these criteria. For Kanner and Eisenberg's

two criteria 220 met these. Nobody met criteria for Asperger's Syndrome. The finding of 4.9 / 10,000 is likely to be an underestimate because it was not a total population study of persons up to 25 years in the E.R.H.A. It is also likely that some mild cases may have been missed and that staff may not have considered the possibility of autism in some persons with severe mental retardation or indeed with normal intelligence and also that some pre-school children may not have come to anyone's attention with autism.

The families were experiencing considerable burden from the person with autism. Social contact variables as well as parental partnership variables in the family and social contact variables outside the family were quite important. It would appear that these variables would have considerable service implications.

Section I

Chapter One

Diagnosis and Differential Diagnosis

This introductory chapter focusses on issues relating to the diagnosis of autism. This is an issue that has aroused a considerable degree of debate since Kanner described autism in 1943. The definition of Asperger Syndrome (Wing, 1981a) first described as 'autistic psychopathy' by Asperger (1944) has also engendered considerable debate. An area of increasing interest is early diagnosis of autism (Dahlgren and Gillberg, 1989; Baron-Cohen *et al.*, 1996). A variety of conditions have to be considered in the differential diagnosis including semantic pragmatic disorder; deafness; blindness; disintegrative disorder; elective mutism; Rett's syndrome; schizophrenia; emotional deprivation; learning disability; right hemisphere learning disability and schizoid personality disorder.

1.1 The Definition and Diagnosis of Autism

Kanner described autism in 1943 and stated that the condition he described "differs . . markedly and uniquely from anything reported so far". He did not attempt to specify strictly defined diagnostic criteria, but presented detailed case histories of 8 boys and 3 girls, noting the following characteristic features:

(1) Inability to relate to people, including members of the child's own family, from the beginning of life.

(2) Mutism or abnormal, largely non-communicative use of language in those who did speak. Pronoun reversal was observed in all children who could speak (8 cases), and echolalia, obsessive questioning and ritualistic use of language in several.

(3) Abnormal responses to environmental objects and events, such as food, loud noises and moving objects. Kanner viewed the child's behaviour as governed by an anxiously obsessive desire for the maintenance of sameness, which lead to a limitation in the variety of spontaneous activity.

(4) Good cognitive potential with excellent rote memory.

(5) "Physically the children were essentially normal". Several children were clumsy in games but all had good fine muscle co-ordination.

Many psychiatrists found that the clinical picture described by Kanner fitted puzzling cases they had observed in their own clinics, but progress in documenting and understanding autism did not follow smoothly. Kanner (1965) complained of two related trends in child psychiatry. Some child psychiatrists did not accept that autism was a distinctive syndrome, and suggested it was fruitless to draw sharp dividing boundaries between autism and other types of atypical development. Others accepted that autism was a syndrome, but applied this fashionable diagnosis far too widely. It "became a habit

to dilute the original concept of infantile autism by diagnosing it in many dispirate conditions should one or another isolated symptom be found as a part feature of the overall syndrome. Almost over night, the country seemed to be populated by a multitude of autistic children". Wing (1976) noted that yet others interpreted Kanner's summary of the features of his syndrome far too narrowly, so that autism would not be diagnosed unless the child showed no sign of awareness of other people, despite the fact that none of Kanner's own cases was this severely impaired.

Kanner was neither the first nor the last investigator to attempt to identify meaningful diagnostic categories among severely impaired children. De Sanctis (1906, 1908) applied the terms "dementia precocissima" and "dementia precocissima catatonica" to conditions characterised by social and cognitive deterioration and stereotyped behaviour following a varying period of normal development. Heller (1930) (translated by Hulse, 1954) described similar conditions for which the term "dementia infantilis" was used. Some of the children these authors wrote about died within a few years following the regression, but, in others, their condition stabilized at a low level of function. In these, the clinical picture was "strongly reminiscent of severe autism associated with severe retardation" according to Wing (1991). Earl (1934) described adolescents and adults who functioned as either severely or profoundly mentally retarded or with no speech or self care but with some motor skills, who were indifferent to people and absorbed in repetitive, stereotyped movements of the fingers, limbs and body. He described these as the "primitive catatonic psychosis of idiocy". Mahler (1952) described a group of children with abnormal social relationships, especially empty clinging to adults, echolalia and repetitive speech on bizarre themes, to which she gave the name "symbiotic psychosis". Rank (1949, 1955) described patients with atypical personality development and Evans-Jones and Rosenblum (1978) described disintegrative psychosis.

Confusion with Bleuler's (1911/1950) use of the term autism to describe schizophrenia in adults lead many clinicians to use the term "childhood schizophrenia" (American Psychiatric Association, 1968; Bender, 1956). Ekstein and Wallerstein (1954) used the term "borderline psychosis". Rutter and Lockyer (1967) used the term "infantile psychosis". At this time childhood schizophrenia, borderline psychosis, symbiotic psychosis and infantile psychosis were used as interchangeable diagnosis. Creak (1961) identified nine points intended to evolve a broader definition of autism that would incorporate childhood schizophrenia. Creak's criteria were based on behavioural observations rather than theory. Nevertheless, they were difficult to use for research purposes because they were never quantified. In addition their lack of developmental perspective made them particularly difficult to use with young children. Although Creak's points included autism with schizophrenia, De Meyer, Churchill, Pontious, and Gilke (1971) found that Creak's main points for childhood schizophrenia corresponded more closely to autism than to schizophrenia. Before trying to make a partial resolution of this very confused diagnostic situation it is important to comment on Asperger's (1944) paper on what he called "autistic psychopathy" which had striking similarities to Kanner's first description of his autistic cases. Asperger's account contains points which contrast with the Kanner prototype of autism. The term "Asperger's syndrome" was first used by Lorna Wing (1981a) when she drew attention to the diagnosis because she felt it would be possible to gain recognition for very able autistic people who did not fit the Kanner stereotype of being silent and aloof. She listed six diagnostic criteria based on Asperger (1944):

(1) Speech - no delay, but content odd, pedantic and stereotyped;

(2) Non-verbal communication - little facial expression, monotone voice, inappropriate gesture;

(3) Social interactions - not reciprocal, lacking empathy;

(4) Resistance to change - enjoy repetitive activities;

(5) Motor co-ordination - gaze and posture odd, gross movements clumsy, sometimes stereotypies;

(6) Skills and interests - good rote memory, circumscribed special interests.

Wing (1981a) modified these criteria, according to her own clinical experience, making three changes:

(a) Language delay - only half the group Wing would label as having Asperger's syndrome developed language at the normal age.

(b) Early development - before age of 3 years the child may be odd, e.g. no joint attention.

(c) Creativity - Wing claims that these children are not creative, and for example do not show pretend play. Rather than being "original" their thought processes were pedantic and inappropriate.

To return to the definition of Kanner's syndrome it is interesting that in 1956 Kanner and Eisenberg modified the criteria for autism given by Kanner in 1943, thereby shifting the parameters within which the syndrome could be diagnosed. They noted that their case material had expanded to include some children reported to have developed normally for the first 18 to 20 months of life before becoming autistic. They also selected two of Kanner's original five criteria as being of primary diagnostic importance and sufficient for identification of autism, namely extreme self-isolation and obsessive insistence on the preservation of sameness. They went on to say that the preservation of sameness must be manifested as preoccupation with "elaborately conceived rituals" since simply repetitive activities may be present in severely retarded children.

In 1973 a collection of Kanner's papers on autism were published. Here Kanner described 34 "psychotic" children, 15 of whom he diagnosed as having early infantile autism, 7 as childhood schizophrenia and the rest as disorders with evidence of organicity. He said this showed "the frequently apparent perplexities of nosological nomenclature".

In 1968 Michael Rutter reviewed the confusion that existed for some years after Kanner's early report of autism with a critical analysis of the existing empirical evidence and proposed four essential characteristics of autism:

(1) A lack of social interest and responsiveness.

(2) Impaired language, ranging from absence of speech to peculiar speech patterns.

(3) Bizarre motor behaviour, ranging from rigid and limited play patterns to more complex ritualistic and compulsive behaviour.

(4) Early onset, before 30 months of age.

These four essential features of autism were adopted by three sets of diagnostic and classificatory schemes that have been widely used by clinicians; the International Classification of Diseases, 9th revision, Clinical Modification ICD-9; (U.S. Department of Health and Human Services, 1980); the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition (APA, 1980); as well as the third edition revised (APA, 1987).

Rutter repeated his review of the literature in 1978 (Rutter, 1978) and again documented the chaos that occurred for some years after Kanner's early report with infantile autism, childhood psychosis, childhood schizophrenia being applied inconsistently to children who had some or all of the clinical features of Kanner's early cases. He suggested the following criteria in relation to behaviour before 5 years of age to define childhood autism:

(1) Onset before the age of 30 months.

(2) Impaired social development which has a number of special characteristics and is out of keeping with the child's intellectual development.

(3) Delayed and deviant language development which also has certain defined features and which is out of keeping with the child's intellectual level.

(4) Insistence on sameness, as shown by stereotyped play patterns, abnormal preoccupations or resistance to change.

Rutter pointed out that intellectual retardation and autism were not mutually exclusive diagnosis as suggested by Kanner. Kanner had said that his autistic patients had good intellectual potential but this was based on the fact that they had good rote memory and ability to do formboard puzzles. Later studies found that many autistic children possessed these skills while remaining very limited in other areas of functioning. The extent of intellectual retardation associated with autism will effect management and prognosis, but I.Q. level is not nowadays regarded as a factor in deciding whether or not the child should be diagnosed autistic.

Criticism of Kanner's account of autism were made in The Emmanuel Miller Lecture 1991 (Gillberg, 1992a) when Christopher L. Gillberg stated that Kanner's description of autism had lead to "stagnation in thinking about autism". He went on to state that "we are constantly reminded that Kanner said it (autism) was affective and that for some reason the fact that Kanner said it was affective was more important than research in intervening years, suggesting that it may not be affective". He went on to point out that Kanner's assertions that these patients were of potentially superior intelligence as well as his thought that they were upper class has been "questioned or disproved". He also stated that Kanner's autism was not a discrete disease entity with one aetiology "but rather is one of several syndromes on a spectrum of autism and autistic-like conditions". He then went on to state that "we have not been able to find any support in the literature for "Kanner's autism" being more valid than other variants of the "triad of social, communication, and

imagination impairments" (Wing, 1989) characteristic of most people with autism and autistic-like conditions and Gillberg (1992a) stated that "I have not been able to find a shred of evidence for a clear distinction between (Kanner) "autism" and other variants, including some cases with so called Asperger syndrome (Asperger, 1944; Wing, 1981a; Gillberg, 1991)".

The ICD-9 (WHO, 1978) and DSM-III (APA, 1980) have similar definitions and diagnostic criteria for autism. In ICD-9 autism is classified as a subtype of "psychosis with origins specific to childhood", whereas in the DSM-III system autism is viewed as a "developmental disorder" and is grouped under the broad class of pervasive developmental disorders (PDDs). The PDDs are defined as a group of severe, early developmental disorders characterized by delays and distortion in the development of social skills, cognition, and communication. In the DSM-III, PDDs include:

(a) Infantile autism (i.e. those with the onset before age of 30 months).

(b) Childhood - onset pervasive developmental disorder (i.e. those with whom the disorder develops after the age of 30 months).

(c) Atypical pervasive developmental disorder.

(d) Residual infantile autism (i.e. once was but no longer meets full criteria of infantile autism).

Cohen *et al.* (1986) also pointed out that in DSM-III system criteria for infantile autism appeared to be overly stringent and did not sufficiently encompass issues of developmental change, i.e. were too "infantile" in nature. The failure to address broader problems in communication and not just language was problematic; many autistic adolescents and adults received the diagnosis of residual autism. Such individuals, however, still were markedly impaired and exhibited features of the disorder. The rationale for including a new diagnostic category (childhood onset PDD) was questionable.

Clearly DSM-III attempted to adopt explicit operational criteria for autism. This raises the issue of what criteria are truly central aspects of autism. Diagnostic criteria are, in fact, complex syntheses of individual features or symptoms of the disorder; the practical delineation and application of such criteria can prove problematic. DSM-III intended to be phenomenologic, atheoretical, and as parsimonious as possible.

Attempts have also been made statistically to establish which symptoms best discriminate autistic from non-autistic youngsters. It is in data from the Rimland checklist (Rimland, 1968, 1971) that Prior Perry and Gajzago (1975) found that only three specific behaviours (the desire for sameness, islets of special ability, and skill in manipulation of small objects) discriminated autistic and non autistic children. Freeman *et al.* (1980) studied 67 behaviours in autistic, retarded and control subjects matched for mental and chronological age and found substantial symptom overlap between groups. The considerable overlap and variability in symptom expression proved problematic in attempts to develop criteria which differentiate diagnostic groups on the basis of exclusive, necessary and sufficient findings. In the past investigators focussed on one particular feature of the autistic syndrome i.e. linguistic (Rutter *et al.*, 1971) perceptual (Ornitz and Ritvo, 1968)

cognitive (Prior, 1979) or social-affective (Kanner, 1943) as if these were isolated processes. However, communication, social development and other cognitive skills emerge in an interdependent fashion over the course of the child's development. The search for a single, unitary, pathogenic explanation for autism is further complicated by the association of autism with various other conditions as well as symptom variability within and between subjects.

Volkmar and Cohen (1988) point out "that DSM-III criteria lacked a developmental focus, criteria appeared to be overly restrictive, and it over-emphasized language (as opposed to communication) problems". It was also considered to be too "infantile" and more appropriate for younger and more handicapped people.

This led to changes which appeared in DSM-III-R (A.P.A., 1987). A precise age of onset criterion was no longer included and it was more developmentally orientated.

The developmental nature of the disorder was meant to be emphasised by its placement on axis 2 of the multiaxial system. The word infantile was dropped from the name of the disorder to emphasise the continuity of the disorder over time. There was an emphasis on social dysfunction, disturbances in communication and imaginative play, and restricted activities - interests which made the diagnosis more consistent with Wing's (Wing and Attwood, 1987) view of diagnosis. To meet the diagnosis for autistic disorder an individual had to have 8 of 16 items of which two had to be from the section dealing with qualitative impairment in reciprocal social interaction; 1 from qualitative impairment in verbal and non verbal communication, and imaginative activity and 1 from the section on restricted repertoire of activities and interests. Onset before 30 months was no longer included as a diagnostic criteria. Some aspects of DSM-III-R appeared to represent considerable improvements over DSM-III e.g. there was more attention to the developmental aspects of the disorder and criteria were more applicable to older and higher functioning autistic individuals (Volkmar *et al.*, 1991). Nevertheless the diagnostic concept was significantly broadened (Volkmar *et al.*, 1988, 1991) with a relatively high rate of "false positive cases" relative to clinician's diagnoses.

Volkmar *et al.* (1988) evaluated the sensitivity - specificity of DSM-III-R criteria in 52 clinically autistic and 62 non-autistic but developmentally disordered cases. DSM-III-R diagnosis were compared both to the clinical diagnosis as well as to DSM-III (A.P.A., 1980) diagnosis. Relative to clinician's diagnosis DSM-III-R had an acceptable sensitivity (.904) but the specificity was low (.645) with a high false positive rate; DSM-III criteria resulted in a somewhat lower sensitivity but higher specificity. This observation was found to be troubling because it complicated comparisons of studies done using different diagnostic criteria. Despite this the revised criteria were much more concrete, observable, and operational than those in DSM-III. It is also of interest that in DSM-III-R the criteria for autistic disorder had been so specified that the presence of 1 or 2 more normal social or communicative behaviours, such as making eye contact, or enjoying a cuddle, did not preclude the diagnosis if other aspects of reciprocal social interaction (e.g. imitation, social play or ability to make peer relationships) were clearly abnormal. Gillberg (1992a) makes an interesting comment on DSM-III-R. He points out that there has been growing concern that the introduction of the "autistic disorder" concept in DSM-III-R might have inflated prevalence figures. He states that this could not explain the high prevalence in published epidemiological studies as they did not use

the diagnosis at all. Finally he states that "the gradually looser autism concepts could have contributed to the steady prevalence rise".

Volkmar (1992) pointed out that with ICD-10 (W.H.O., 1993) cases of younger autistic children were somewhat more likely to be missed. He found that ICD-10 had a sensitivity of .79 and a specificity of .89. He again emphasises the absence of a diagnostic marker or "goal standard" for autism. ICD-10 and DSM-IV (A.P.A., 1994) systems both identify three areas of deficit required for a diagnosis of autism:- communication, social development and restricted and repetitive behaviours and interests. Both require the recognition of some type of abnormality prior to the age 36 months. ICD-10 and DSM-IV are multiaxial frameworks and have an explicit recognition of the need to consider intellectual level, specific developmental delays, other psychiatric disorder and psychosocial factors in each diagnostic decision. It is obvious that the conception of PDDs in ICD-10 is a "splitters" approach.

DSM-III-R had a new category of pervasive developmental disorder not otherwise specified (PDDNOS). These individuals had some of the characteristics of PDD but not enough to qualify for a diagnosis of autistic disorder. The PDDNOS of DSM-III-R is more or less equivalent to the atypical PDD plus the residual infantile autism of DSM-III. Tsai (1992) states that PDDNOS refers to the whole spectrum of atypical autism as well as the non-autistic forms of PDDs, including a form of Asperger's syndrome, a mild form of Rett syndrome, and disintegrative disorder. Mayes *et al.* (1993) points out that PDDNOS is probably much more common than strictly defined autism. The fact that there are so few studies on this condition appears to reflect marked differences in the use of the diagnostic concept and the lack of specific diagnostic criteria for the condition (APA, 1987). Although less commonly studied than autism, some evidence for the validity of the condition exists, for example, on the basis of natural history and prognosis (Dahl *et al.*, 1986; Provence and Dahl, 1987; Rescorla, 1986; Sparrow *et al.*, 1986). Such children typically exhibit more differentiated social relatedness and better cognitive and communicative skills than most autistic children (Cohen *et al.*, 1986). Clearly PDDNOS is essentially a negative definition i.e. the disorder is not autism and therefore given the nature of the category no explicit criteria are provided in DSM-III-R. When Mayes *et al.* (1993) attempted to differentiate PDDNOS from autism or language disorders they found that the items that distinguished children with PDDNOS from those with autism related to the degree of socialization and relatedness with children with PDDNOS showing less severe disturbances in relatedness. That they had greater difficulty in discriminating PDDNOS from autism was not unexpected in that children with PDDNOS would be expected to generally resemble children with more classical autism than those with language disorder. Indeed these were young subjects and whether the same items would discriminate with older populations is uncertain.

In 1995 Serra *et al.* pointed out that "the fact that the diagnosis of PDDNOS is used for a very heterogeneous group of children, causes serious problems not only for research, but also for the development of adequate treatment facilities". Serra *et al.* (1995) go on to point out that this lack of explicit diagnostic criteria have lead to several attempts to provide criteria for distinguishing subgroups within the PDDNOS group. They point out that Wing and Attwood (1987) describe a sub-classification of the autistic spectrum into three different groups based on the quality of social interaction; aloof, passive, and active but odd. Cohen *et al.* (1987) suggest the term Multiplex Developmental Disorder for children who show impairments in social behaviour and social sensitivity, in the

regulation of affective state and anxiety, and in cognitive processing. Gillberg (1983) describes a group of children with deficits in attention, motor control and perception (DAMP). Often these children also have social and communicative problems, semantic-pragmatic problems and a restricted repertoire of activities. This group of children was not explicitly described as a subgroup of PDDNOS group but might consist of children who could be classified as such according to Serra *et al.* (1995). Minderaa (1989) state that many children with a PDDNOS experience problems in contact and communication, in motor development, in language development and in sensory information processing. Problems tend to be less severe than in the case of autism. Minderaa and van Engeland (1992) suggest that the most important problem of children with a PDDNOS is their difficulty in understanding and interpretating information about the social environment and in regulating their behaviour to fit the social context. Most people agree that the central problems of PDDNOS children are social interaction and communicative problems. Gillberg (1991) hypothesizes that these social interaction and communicative problems might be caused by a social-cognitive deficit. The ability to conceptualise other peoples' inner worlds and to reflect on thoughts and feelings might be the underlying problem, not just of autism but of a whole spectrum of developmental disorders, including PDDNOS. The results of a study of emotional role - taking in children by Serra *et al.* (1995) provided some empirical support for Gillberg's (1991) view. They perform less well on role - taking tasks as compared to normal healthy children. Nevertheless Bishop (1995) has described PDDNOS as "a carbuncle on the face of child psychiatry". She expresses a wish for a more satisfactory form of terminology than PDDNOS because of the number of children who would come under this label.

There has also been criticism of the introduction of the word "pervasive" as a compulsory prefix to "developmental disorder" when referring to autism and autistic-like conditions. Baird *et al.* (1991) point out that autism and autistic-like conditions are not necessarily "pervasive". They point out that these conditions constitute disorders in which there are specific deficits in social cognitive functioning. They believe that when autistic-like conditions were not associated with mental retardation they might be classified more appropriately as coming within the specific developmental disorders category. Rutter and Schopler (1992) disagreed with these arguments. Rutter and Schopler (1992) presumed that the specific psychological deficit suggestion referred to the finding that autistic individuals lacked a "theory of mind" (Baron-Cohen *et al.*, 1985). They felt it was uncertain whether the cognitive deficit was as specific as first supposed, as Ozonoff *et al.* (1991a) showed that executive planning deficits were more characteristic of autism. The "theory of mind" hypothesis of autism holds that autistic individuals are unable to attribute beliefs and other mental states of people.

Happe (1994) is critical of the use of the term "autistic-like" because by using the term "autistic-like" diagnosticians are maintaining an incorrect stereotype of the way in which autism can be manifest. She feels the term is imprecise and the children so labelled may not receive their educational rights which a diagnosis of autism should confer. She also points out that people use this term when they are describing a child who may be more able, than most autistic children. She is willing to accept the term "mild autism" but disagrees with the word or with the phrase "autistic-like" because this suggests a fundamental handicap other than autism. She also points out it can be used when somebody is referring to some aspect of a child's behaviour but says it should not be used for a child that has say a communication problem but no imagination and socialisation handicaps, since autism is defined as a syndrome by the concurrence of the triad of

impairments in social relationships, communication and make believe play as described already by Wing and Gould (1979).

Wing (1987) described the autistic continuum or spectrum as more or less equivalent to the group Pervasive Developmental Disorders as described in DSM-III-R. Tsai (1992) summarises the autistic continuum as containing atypical autism or PDDNOS, Kanner autism, Asperger's syndrome, Rett's syndrome, disintegrative disorder and low-moderate autism. According to Wing and Gould (1979) Kanner autism is viewed as a part of a "continuum" of autistic disorder. The central problem of the continuum is an intrinsic impairment in development of the ability to engage in reciprocal social interaction. The manifestations of the social and other problems of the continuum vary widely in type and severity. Wing and Gould also emphasised that the term continuum represents a concept of considerable complexity, rather than simply a straight line from severe to mild. Thus, Wing and Gould's autistic continuum has an even broader definition and set of diagnostic criteria of autism. It includes the autistic disorder of DSM-III-R at one end of the continuum and has the PDDNOS at the other end. This diagnostic system is based on a "lumpers" approach. Tsai (1992) claims that it includes too heterogeneous a group of individuals, and hence is problematic for the study of external validity (i.e. to what extent does autism differ from other disorders with autistic-like symptoms on variables that are external to the diagnostic criteria, such as family history of psychopathology, markers of aetiology, clinical course, outcome, or response to the treatment or treatment needs. The alternative approach is the "splitters" approach which breaks down symptom clusters into smaller, homogeneous, and meaningful subgroups as in ICD-10 diagnostic classification (W.H.O., 1993).

Bishop (1989) points out that the more studies that are conducted into the questions of diagnosis of autism, the stronger becomes the impression that difficulties in recognising the boundaries of autism are not solely a consequence of the subjective and elusive nature of the symptoms. She feels that we are dealing with a disorder that has no clear boundaries. Wing (1988) has argued that rather than thinking rigidly in terms of a discrete syndrome of autism, we should be aware that there is a continuum of autistic disorders. Wing regarded social impairment as a central feature of such a disorder. She pointed out that children with this social impairment are characterized by a triad of deficits in social recognition, social communication and social understanding. In each of these domains, a wide range of severity of impairment is recognised. In this sphere of social communication, for instance, the severely impaired child may make no effort to initiate communication at all; the moderately impaired children may use language to achieve some end, such as obtaining an object; the mildest form of impairment corresponds to subtle difficulties in recognising the need of conversational partners. Wing (1988) would regard a child as falling on the autistic continuum provided they showed this triad of social impairment in relationships, communication and imagination and understanding irrespective of other symptoms. However, she noted that impairments in other areas do tend to co-occur with the social triad, in particular repetitive and stereotyped activities, poor motor co-ordination and abnormal responses to sensory stimuli. The autistic continuum implies a single dimension in which a condition such as Asperger's syndrome constitutes a milder form of the same underlying disorder that is seen in autism. However, clinical accounts suggest that conditions resembling autism do not differ just in terms of severity, but also in pattern of symptoms. Thus the label Asperger's syndrome is typically applied to clumsy children with circumscribed interests, with early language development not delayed, and who may have a verbal I.Q. well above

performance I.Q. (Wing, 1981a). Bishop (1989) points out that language impaired children fitting the picture of semantic-pragmatic disorder typically first present with delayed language development and evident comprehension problems, and have a marked I.Q. discrepancy in favour of performance I.Q. Happe (1994) felt that speech therapists who used the diagnosis semantic pragmatic disorder (Rapin and Allen, 1983) very frequently in the mid - 1980s ignored the diagnosis of autism because they were using a conception of autism, a too strong adherence to a Kanner - type stereotype which lead them to discard the diagnosis of autism prematurely. Indeed Brook and Bowler (1992) after reviewing empirical studies of children with semantic and pragmatic impairments, concluded that these children could be considered to lie within the autistic continuum. Bishop (1989) suggested that a continuum approach should also be taken in this area. Happe (1994) goes on to state that autism can appear in a great range of manifestations - a spectrum of disorders. She felt it was easiest to recognise individuals at the mid point of this spectrum. She felt that cases at either extreme presented a problem for diagnosis; at the low ability end of the spectrum it may be hard to diagnose autism because the individual's level of functioning is so poor that social, communicative and imaginative functioning may be very low but still in line with the general developmental level (e.g. below 20 months). At the upper end of the spectrum, autistic people may have devised coping strategies which disguise their real problems - as with the autistic adolescent who greets visitors to the school so nicely that they question the diagnosis of autism but who repeats exactly the same greeting in a stereotyped way 20 times a day to people he already knows.

Happe (1994) states that a large number of syndromes similar to autism have been suggested and given different names. She is uncertain which of these fall within the autistic spectrum (differing only in degree of impairment), and which represent distinct disorders (differing in the nature of the underlying impairment). She points out that if we define handicap in terms of problems with communication, socialization, and imagination impairments, then a child who shows flexible and creative make-believe play cannot be said to be autistic. On the other hand a child who shows subtle but characteristic pragmatic impairments, rather than the more typical gross deficits, could still be diagnosed autistic, without stretching the diagnostic boundaries past usefulness.

It is also worth pointing out that Shea and Mesibov (1985) stated that "classical cases (autism) are greatly outnumbered by cases with mixed, impure and partial characteristics".

Le Couteur (1993) states that it is unlikely that any of the present diagnostic criteria will exactly match the cause or causes of autism. She points out that there is clearly a need to continue research into the broader phenotype of autism.

Gillberg and Coleman (1992) note that the Wing and Gould (1979) study was a landmark study and showed that "Kanner autism could be identified among the Triad patients, there was no indication that they differed in any meaningful way from other cases on the spectrum. The validity of Kanner syndrome has been seriously challenged by this study". As described by Christopher Gillberg and Mary Coleman in their book "The Biology of Autistic Syndromes" (1992) Christopher Gillberg and co-workers confirmed Wing and Gould's (1979) findings in a study of all 13 to 17 year old children with mental retardation in Goteborg and rate of 20 per 10,000 children had a combination of mental retardation and the triad of social, language and behavioural impairments (including

nuclear and non-nuclear autism). Nuclear autism is a narrow definition as defined already in this chapter by Kanner.

Gillberg (1995b) points out that the "evidence for a specific 'nuclear autism' disease entity is lacking". Gillberg (1995b) has used the term autism spectrum disorders to cover a range of triad disorders including 'Kanner' autism, Asperger syndrome and other autistic-like triad conditions (including 'autistic traits' encountered in DAMP and mental retardation). DAMP refers to children with deficits in attention, motor control and perception.

Szatmari (1992) reviewed the validity of autistic spectrum disorders (ASD). He included in this previous terms such as atypical autism, autistic-like, Asperger syndrome, and autistic tendencies. As far as internal validity was concerned in relation to ASD subtypes he pointed out that cluster analytic studies have demonstrated that atypical forms of PDD can be distinguished from autism using statistical techniques, and epidemiologic studies have confirmed that such children can be identified in community samples separate from autism. However, there are no data confirming that the diagnostic criteria for ASD can be applied in a reliable fashion nor that such criteria would not overlap unnecessarily with criteria for autism. He points out that this was troublesome since a category should demonstrate potential for measurement before it can be considered useful. What evidence there is however, does indicate that certain clinical differences exist between autistic spectrum disorders and autism; that is, that the ASD children tend to have fewer autistic symptoms, greater fluency in language, and later age of onset. Szatmari (1992) concludes that as a diagnostic category autistic spectrum disorders appear to have limited evidence of internal and external validity. Three subgroups of ASD children can be distinguished from autism on clinical grounds; a low functioning atypical group, a high functioning atypical group, and Asperger syndrome. The outstanding issue is whether the clinical differences between autism and ASD are simply a function of severity or developmental level. The question is whether the clinical and aetiologic differences still hold if the autistic and ASD groups are matched on a measure of developmental level such as I.Q.? Szatmari *et al.* (1989) and Gillberg (1989a) studies suggest that clinical differences persist but further replication is needed. There are problems with sub-typing disorders from the autistic spectrum disorder. Szatmari (1992) points out that by "carving up" these dimensions at "false joints" and by rigidly specifying diagnostic criteria for subtypes on the spectrum the concept of varieties of qualitative impairments in socialisation, in verbal and non-verbal communication, and in imaginative activities could be lost.

1.2 Asperger's Syndrome and Autism

As well as striking similarities to Kanner's first description of autism, Asperger's account contains points which contrast with the Kanner prototype of autism. In particular Asperger's cases appeared to have had better language abilities, more motor difficulties and perhaps more original thinking capacities than Kanner's subjects. These differences have led people to wonder whether Asperger was, in fact, describing a rather different group of children - perhaps a special subgroup within the autistic spectrum. For Wing (1981a) Asperger's syndrome formed a means of extending the autistic spectrum to previously unrecognised, subtle degrees. However it is important not to forget Asperger's conviction that the pattern of impairments he described could occur in children of low intelligence as well as those of high ability. Diagnostic criteria are also complicated by

the fact that Wing (1981a) and others have pointed out that the child may look typically Kanner - type autism in infancy and yet develop into a more Asperger's syndrome like adolescent. Gillberg (1996) points out that some children at age 4/5 years are clinical autism and then when you meet them 5 years later they are a very good example of Asperger's prototype. There seems to be good reason to connect Asperger syndrome and autism despite the suggestion by Wolff (1991) that Asperger's own subjects were more akin to children with schizoid disorders than to those with autism. As Happe (1994) points out a growing number of family studies have found a concurrence of Asperger's syndrome and autism in the same family to be higher than expected by change. In a family treated for many years by the author (M.F.) and described in the literature by Bowman (1988) the four sons and the father all showed differing degrees of autistic handicap from the mildest case, which looked like Asperger's syndrome, to the most severe, a typical "Kanner case" where autism was compounded by mental retardation. Also Burgoine and Wing (1983) report a set of triplets who span a range from Asperger's syndrome to classic Kanner type autism. More recently Gillberg (1991) has described the families of 6 Asperger's syndrome individuals between the ages of 6 and 33 years. He found that two of the families had a first degree relative afflicted with autism. In addition, Asperger's syndrome or Asperger-like traits could be identified in at least one first or second degree relative of each of the children. He stated that "all six cases had a close relative with Asperger syndrome".

Asperger by 1979 believed that the children he described were separate from Kanner's autistic children. Nevertheless he did recognise that the two groups had a good deal in common. Asperger believed that his subjects had good logical and "abstract" thought, good surface language and a better prognosis than Kanner's autistic patients. This independent view was supported by van Krevelen (1971). Van Krevelen (1971) claimed that autistic children acted as if others did not exist while children with Asperger's syndrome evade other people, of whom they are aware. Burd and Kerbeshian (1987) quote Kanner's commentary on Robinsons and Vitale's (1954) report of children with circumscribed interest patterns which he says are not autism.

Gillberg (1996) points out that ICD10 and DSM-IV criteria for Asperger's syndrome "require that there should be no language abnormality" during first three years of life and there should be normal social curiosity during the first three years of life" and he points out that he has "problems with that definition" as "in real life" he does not see those Asperger children who have this normal curiosity and completely normal language development.

Burd and Kerbeshian (1987) claim that these children would fit the description of Asperger's syndrome. Szatmari *et al.* (1986) claimed that not all children with Asperger's syndrome are autistic at least as judged by early history and prognosis. Happe (1994) again questions their diagnosis of autism and claims that their subject Mary sounded very typically autistic. Happe (1994) goes on to say that experimental studies have failed to reveal any striking differences between groups of autistic and groups of "Asperger's syndrome" children. Szatmari *et al.* (1990) compared high functioning autistic subjects, Asperger's syndrome subjects and outpatient controls on a number of tasks. They found that very few major differences emerged between the Asperger's syndrome and high functioning autism groups. They concluded that "there were no substantive, qualitative differences between Asperger's syndrome and autistic groups, indicating that Asperger's syndrome should be considered a mild form of high functioning autism". Gillberg (1996)

points out that most authors see an autistic patient with I.Q. above 70 as high functioning. Gillberg (1996) points out that "one clinician would give a diagnosis of high functioning autism and another Asperger Syndrome". Gillberg (1996) noted a stronger family history of Asperger's syndrome or Asperger-like symptoms in Asperger's syndrome patients. Klin *et al.* (1995) showed that Asperger syndrome and high functioning autism differed on a number of neuropsychological areas. Ozonoff *et al.* (1991b) studied Asperger's syndrome and high functioning autistic patients and found that only the high functioning autistic group showed significant impairments on theory of mind tasks and verbal memory tasks. Happe (1994) cast doubt on their diagnostic criteria.

Many people according to Happe (1994) are content to explain the differences between Asperger's syndrome and autism on the basis of severity. If Asperger's syndrome is different from Kanner type autism only because of a milder handicap, then any autistic person with mild features will have Asperger's syndrome. This is implicit in Wing's (1981a) conclusion that there is no distinction between Asperger's syndrome and higher level autism, being just part of the autistic continuum. At the same time she argued that Asperger's syndrome is useful practically, as a label for less typical autistic patients who do not fit the pattern of the child who is agile, but aloof and indifferent to others, with little or no speech and no eye contact.

Gillberg (1989a) found the following differences between Swedish children with Asperger's syndrome and autistic children matched for I.Q. and age. He found that the frequency of Asperger's syndrome-like problems in the parents was higher for Asperger's syndrome children; motor clumsiness was more common in the Asperger's syndrome children. Circumscribed interests were found in 99% of Asperger's syndrome cases and only 30% of the persons with autism.

Gillberg (1995b) states "that there is important overlap between severe DAMP (Deficits in Attention, Motor control and Perception) and so called Asperger syndrome and 'autistic traits'. Gillberg and Gillberg (1989) state that individuals with severe DAMP often show autistic traits and the majority diagnosed as suffering from Asperger syndrome meet criteria for DAMP".

A study by Rumsey and Hamburger (1988) also suggest that there is a group of "high-functioning" autistic individuals who do not fit the description of Asperger's syndrome. They compared 10 "able autistic" men of normal I.Q. with 10 "normal" controls. This result strongly suggest that high ability in terms of I.Q. at least, is not enough to transform a typical autistic picture into an Asperger's syndrome picture. Equally Tantam (1988a, b) found adults whom he diagnosed as having Asperger's syndrome, who had low intellectual ability. Ehlers and Gillberg (1993) in a population study found a prevalence of 36 per 10,000 school age children of definite cases of Asperger Syndrome and 60 per 10,000 if definite and suspected cases were included. Happe concluded (1994) that a "mild form of high functioning autism" is not necessarily Asperger's syndrome - one may have a relatively mild handicap and be autistic without conforming to the Asperger's syndrome subtype. She pointed out that the Asperger's syndrome label is used to mark a subgroup of autism which is at the more able end of the spectrum in terms of social and communication handicap.

In conclusion there is controversy over the exact nature of Asperger's syndrome (Lord and Rutter, 1994) and how it compares to autism without mental retardation and whether it

can occur at all in mentally handicapped individuals (Szatmari *et al.*, 1989; Ozonoff *et al.*, 1991b). There is also a lack of clarity about how Asperger's syndrome fits with the schizoid personality (Wolff, 1991). Lord and Rutter (1994) point out that there are individuals "who have milder symptoms of all sorts" and have less restricted interests and fewer bizarre behaviours than classically autistic subjects. Finally Lord and Rutter (1994) state that "whether or not the differences between autism and Asperger's syndrome are qualitative or quantitative has yet to be determined". Once again diagnostic difficulties have inhibited progress.

1.3 Early Diagnosis of Autism

For the early detection of autism in evaluating autistic symptoms it is necessary to take into account the age of the child, and even more importantly, its mental age. There are behaviours which children cannot show below a certain mental age. For instance, below two years, the average child cannot be expected to talk in grammatical sentences. Frith (1989) states that another example is imagination in a child of less than 9 months, because the criterion "lack of imagination" becomes non applicable because imagination is not evident at the 9 month level. Similarly abnormal prosody or abnormal speech cannot be rated in a child who is preverbal or mute. This means that from a diagnostic point of view children at lower mental ages would therefore have to have much more than 50% of (applicable) symptoms positive to be diagnosed autistic. Not surprisingly the DSM algorithm yields a higher false negative rate for chronologically younger children, to ones most likely to be undergoing diagnostic evaluation and the ones most likely to be at the lowest mental ages (Siegel, 1991).

As Gillberg and Coleman (1992) point out there are limited studies of the early diagnosis of autism. One study that has been done by Dahlgren and Gillberg (1989) used a 130 item questionnaire completed by mothers of sex, age and I.Q. matched mentally retarded and population-representative normal children as well as by the parents of children with autism. This was a retrospective study. The items that were found to discriminate autism from mentally retarded and normal functioning children were mainly abnormalities of play, social isolation and peculiarities of gaze and strange reactions to sound.

It has been suggested that an infant with autism may be born with such sensitivity of the tactile system that the child screams when held and the mother has to try and feed the infant without touching him or her (Coleman, 1989). Clinical experience suggests that many parents notice something wrong with their child from almost birth (Gillberg, 1984). Gillberg (1989b) suggested a screening model for autism in infancy. This was to be carried out at the well baby clinic at ages 10 months and 18 months. It includes:

A parental checklist which asks the following questions:

(1) Do you consider your child's eye to eye contact to be normal?

(2) Do you think that your child listens to you or has normal hearing or does your child react only to particular sounds?

(3) If there are or have been any feeding problems or abnormal behaviours in connection with feeding, what were they?

(4) Is your child comforted by proximity or body contact?

(5) Does your child oppose body contact?

(6) Does your child show any interest in his / her surroundings?

(7) Does your child often laugh or smile quite unexpectedly?

(8) Does you child prefer to be left alone?

(9) Is your child on the whole like other children?

This is followed by the following features being examined systematically:

(1) Hand stereotypies (including strange looking or posturing of hands).

(2) Avoidance of gaze contact.

(3) Stiff, staring gaze.

(4) Rejection of body contact.

(5) No or very variable reaction to strong, unexpected noise.

(6) Obvious lack of interest (e.g. does not show interest in peek-a-boo games).

Gillberg, Ehlers *et al.* (1990) in a study of autism under 3 years using DSM-III-R criteria (APA, 1987) found that two-fifths had an associated medical diagnosis. When followed up for a period from several months to several years a diagnosis of autistic disorder was confirmed in 75% of cases. 90% of the mothers knew something was wrong before the child's first birthday. Peculiarities of gaze, hearing, play and autistic aloneness tended to be symptoms most commonly reported. What parents noted was a diffuse concern about something "not touchable" or "not graspable". It has been noted that abnormal responses to sensory stimuli are among the most characteristic group of symptoms in autism cases referred in infancy (Gillberg, 1989b).

Gillberg (1995a) summarized the early detection of autism work when he stated that an early screening test for autism contained a set of 22 questions "aimed at the parent and pertaining to the child's behaviour in the first few years of life with high discriminative validity for autism both in retrospective and prospective studies" (Gillberg *et al.*, 1990). He referred to this instrument as the SABO-2 (Schedule for Autistic Behaviour in Children 0 - 2 years of age).

From one of the author's (M.F.) experience the Childhood Autism Rating Scale of Schopler *et al.* (1988) has been useful for children aged 3 - 4 years onwards. Baron-Cohen, Allen and Gillberg (1992) developed a checklist for autism in toddlers. This was to be used by general practitioners and health visitors at 18 months developmental follow ups. The instrument was called the Checklist for Autism in Toddlers. It focussed on pretend play, joint attention, pointing, social interest and social play. More than 80% of a

randomly selected control group (at 18 months) passed items. No child from the control group showed problems in key areas. By contrast, 4 out of 41 high risk children (children who had a sibling with autism) failed on two or more key items. Follow up at 30 months found that these four children received a diagnosis of autism. This suggests that at 18 months by looking at specific deficits in areas of social, communicative and imaginative competence (as described by Wing and Gould, 1979) helps identify children with autism. Gillberg, Ehlers *et al.* (1990) point out that autism needs to be recognised in infancy, and the focus has to be shifted from the typical speech-language problems to abnormal perceptual responses and various social dysfunctions. Baron-Cohen *et al.* (1996) studied the sensitivity and specificity of an instrument CHAT (Checklist for Autism in Toddlers) to screen for autism at 18 - 24 months of age. Normal children pass the following items at 24 months:

(1) Protodeclarative pointing.

(2) Gaze monitoring, and

(3) Pretend play.

These are the items that are typically abnormal in children with autism (Baron-Cohen *et al.*, 1992). Baron-Cohen *et al.* (1996) screened 16,000 18 month olds. This was "not an epidemiological study and was not totally comprehensive of the area" studied (Cox *et al.*, 1995). The CHAT has questions to be administered to mothers and there are also items that relate to observations to be made by the person administering it about the child.

In the study they identified a group with an autism risk who failed on protodeclarative pointing, gaze monitoring and pretend play. They also identified a group which they called Developmental Delay and who failed on either protodeclarative pointing and pretend play or both. There was also a normal group.

The next stage involved administering the Autism Diagnostic Interview (ADI) (Le Couteur *et al.*, 1989) to parents and also the children were seen under direct assessment to determine if they met ICD10 criteria. Of the 16,000 screened 33 failed the CHAT first time. This was followed by a second screening and on this occasion 12 children failed on the 3 items protodeclarative pointing, gaze avoidance and pretend play, and of these 12 ten met criteria for autism on the ADI. There was a 16.2% false positive rate. It appears now that the rate of autism is higher than the 10/16,000 as some were negative on the CHAT and later were diagnosed as autistic. The 10 positives for autism were again diagnosed as autistic at $3^1/_2$ years of age. The CHAT has good specificity but less good sensitivity. This finding will lead to a further inflation of the prevalence figures for autism according to Gillberg (1995c).

Differential Diagnosis

Differential diagnosis consists of discriminating autism from other psychiatric and developmental conditions that lead to abnormalities in language, play and social development.

1.4 Semantic Pragmatic Disorder

Bishop (1989) recommends that the term Semantic Pragmatic Disorder be used for children who are not autistic but who initially present with a picture of language delay and receptive language impairment, who then learn to speak clearly and in complex sentences, with semantic and pragmatic abnormalities becoming increasingly obvious as their verbal proficiency increases. Children with semantic-pragmatic disorder are sometimes described as egocentric, with poor social skills making them incapable of getting on with their peers, instead showing affection only to adults. Such descriptions according to Happe (1994) are reminiscent of Asperger's original cases. Happe (1994) goes on to say that nothing in the exploration of these children by Bishop and Adams (1989) as well as by Adams and Bishop (1989) contradicts the idea that their problems resemble autism or Asperger's syndrome. Indeed Brook and Bowler (1992) after reviewing empirical studies of children with semantic and pragmatic impairments, concluded that these children could be considered to lie within the autistic continuum. Bishop (1989) in discussing the boundaries between autism, Asperger's syndrome and semantic-pragmatic disorder suggested a continuum approach should be taken in this area. She suggests not just a single continuum of severity, but two dimensions in order to capture the differences in pattern of symptoms between the disorders. She describes different but overlapping areas on a graph where the x axis is meaningful verbal communication and the y axis represents interests and social relations (both ranging from abnormal to normal). However, as Happe (1994) points out "this presupposes that there is no necessary relation between social and communicative competence - since such a graph would be pointless if all subjects with mild social deficits necessarily had mild communicative deficits and so on". Happe (1994) does mention that "this assumption may be incorrect - there is good reason to believe that social and communicative abilities may rely on many of the same cognitive mechanisms. It is clear that further research is necessary, however to assess whether communication problems (in the area of pragmatics, rather than language itself) can be found in children without any degree of autistic social and imagination impairment. Only if this can be shown to be the case will the term 'semantic pragmatic disorder' have a useful role to play" (Happe, 1994).

1.5 Deafness

Autistic children are often thought initially to be deaf. Formal testing resolves this quite quickly. Of course it is possible for children to have autism in addition to deafness.

1.6 Blindness

Sometimes autistic children are first thought to be blind.

1.7 Asperger's Syndrome

This has been covered earlier in the chapter.

1.8 Disintegrative Disorders

Disintegrative disorder or Heller's disease (1930) occurs when normally developing children show marked behaviour changes and regression after the age of two often in association with some loss of co-ordination and bowel or bladder function. (Corbett *et al.*, 1977, Volkmar and Cohen, (1989). These children show social withdrawal, reduced response to sounds, complete loss of communication and unusual sensory behaviours with a development of hand and finger stereotypies not unlike those of autistic children. They differ from autistic children with their loss of motor and self help skills. This condition has sometimes been linked to measles and encephalitis, cerebral lipoidoses and luekodystrophies. Usually no definite causes are found. Often the regressions plateau but sometimes the deterioration continues (Corbett *et al.*, 1977). Gillberg (1995b) uses the label 'autism spectrum' disorder to cover autism, 'Asperger syndrome', childhood disintegrative disorders and 'other autistic-like conditions'.

1.9 Elective Mutism

Sometimes electively mute children can be socially withdrawn and unresponsive but as a rule they do not show the specific abnormalities of language associated with autism except for delay and articulation problems in some cases (Kolvin and Fundudis, 1981).

1.10 Rett's Syndrome

This syndrome has quite a different course from autism and is found exclusively or almost exclusively in girls. There can be autistic-like behaviour in toddlers and pre-school children (Hagberg *et al.*, 1983). Generally there is the appearance of normal development in the first year but then head growth begins to decelerate and over the next two years there is a loss of purposive hand skills and verbal communication if verbal communication has already been in evidence. There is also evidence of social impairment and stereotypical hand wringing or hand clapping midline movements and hyperventilation can be quite common. There is also evidence of gait and truncal ataxia between one and four years. Over the years children with Rett's syndrome show an increase in motor and mental handicaps although social interest may seem to increase to that of children within the limits profound mental handicap. The differential diagnosis is not usually difficult after the age of 4 or 5 years (Olsson and Rett, 1987, 1990). Gillberg (1995b) does not treat Rett's syndrome as one specific variant of autistic-like conditions. He points out that "Rett's syndrome just like tuberous sclerosis, often has a course involving a protracted period of autistic and autistic-like symptoms". He suggests that Rett's syndrome should be diagnosed on another axis for associated medical conditions.

1.11 Schizophrenia

Dykens *et al.* (1991) point out that it is not difficult to distinguish schizophrenia from autism except in rare cases of high functioning autistic adolescents whose unusual thought processes may sometimes sound as if they are delusional. Children with schizophrenia do not show the language abnormalities or difficulties in language comprehension of autistic children (Asarnow *et al.*, 1987). Cantor *et al.* (1982) suggest

that there is a particular pattern of early onset schizophrenia in children with hypotonia, good eye contact, presence of thought disorder, delusions and hallucinations and often a family history of schizophrenia.

Lord and Rutter (1994) point out "that the nosological validity of this group is uncertain". Tsai (1992) points out that almost all autistic people have an onset before 5 years with schizophrenia having an onset in the pre-adolescent or adolescent period (Kolvin 1971). Persons with schizophrenia can be differentiated from persons with autism on the basis of age of onset, developmental history, clinical features and family history (Tsai, 1992). Again Asarnow *et al.* (1987) found that schizophrenic and autistic children did not significantly differ on verbal and perceptual organization factors, but that schizophrenic children had significantly lower scores on the freedom from distraction factor (including attention, short term memory, visual motor co-ordination, speed of responding and mental arithmetic) than the non-retarded (higher functioning) autistic children.

Torrey (1987) points out that schizophrenia has a whole life prevalence of a little less than 1%, and an incidence of about 0.1% per year. Werry and Taylor (1994) point out that the frequency of early onset schizophrenia is unknown and that very early onset schizophrenia is clearly rare. Lewin (1988) has shown a slight male preponderance. An average episode lasts about 1 year and probably longer in very early onset schizophrenia (Asarnow *et al.*, 1991).

1.12 Emotional Deprivation

Sometimes children who have experienced severe neglect show language delay, abnormal social behaviour and sometimes unusual habits and motor stereotypies (Skuse, 1984). These children tend to show normal social reciprocity when relationships are established and do not show the broader communication abnormalities associated with autism.

1.13 Learning Disability (Mental Retardation)

There is sometimes a delay in the diagnosis of autism because of associated learning disability (mental handicap). When children with autism present to professionals they may focus on the mental handicap and not detect the autism. Clearly some children with mental handicap can have some features of autism without having the triad of social impairments of Wing and Gould (1979). Wing (1981b) found that the triad of social, play and language impairment which she identified as central to autistic disorder was strongly associated with I.Q. (a rate of 1.8% in the I.Q. 50 - 69 range, extending to 82% in the 0 - 19 range). Lord and Rutter (1994) have pointed out that some researchers have interpreted this association as meaning that there is an invariant relationship between low I.Q. and autism. They point out that this is not the case. Indeed autism rarely occurs in Down's syndrome individuals despite their mental handicap (Wing and Gould, 1979). They go on to point out that the familial loading associated with autism tends to refer to the language and social abnormalities in individuals of normal intelligence; and there is no loading for mental handicap as such. They reject the concept of autism as a concomitant of mental handicap. Nevertheless three quarters of autistic individuals have I.Q. below 70 and I.Q. is the most powerful predictor of outcome in autism (Venter *et al.*, 1992).

Wing and Attwood (1987) point out that these persons often have simple bodily stereotypies, such as rocking or finger flicking, but observation of social responsiveness allows a differential diagnosis to be made even at this level of function. Some simple stereotypies can occur in young retarded children with mental ages above 20 months, but, if they are not autistic, these do not dominate the activity pattern, and mental age appropriate pretend play will also been seen.

Frith (1989) point out that it is conceivable as Goldstein and Lancy (1985) suggested that "the shape of the distribution of I.Q. test scores for the autistic population is the same as for the normal population, just that the mean is depressed by about 50 I.Q. points". This depression of I.Q. scores would be due to brain impairment but there would still be some children with relatively high scores. Frith (1989) concludes that "if so, then even the most able autistic children would show diminished performance - compared to their hypothetical functioning without autism".

Rutter et al (1993) points out that familial loading in autism is significantly associated with verbal I.Q.. One is also reminded of Kanner's (1943) erroneous view that the low I.Q. often found in autistic individuals was not "real". Rutter (1979) showed that I.Q. scores in autism have the same properties found in other groups. Almost 70% - 80% achieve I.Q. scores on standardized tests in the mentally retarded range, with major proportion scoring in the moderate to severe ranges of mental retardation (Wing and Gould (1979). Gillberg (1992a) has pointed out that the rate of autism and autistic-like conditions associated with mild mental retardation has remained static between 1980 and 1988. He also points out that in Sweden "autism associated with immigrant status, severe mental retardation and near normal or normal intelligence, on the other hand has shown an increase". He noted the "very considerable increase in the numbers of cases diagnosed with "infantile autism" among children with severe mental retardation" and also noted the "increased autism sensitivity among staff and parents" to the realization that autism can exist among those with severe mental retardation. As Frith (1989) and others have shown autistic individuals can have unusual talents as well as deficits i.e. idiot savant talents.

From a legal point it is important that their (persons with autism) special needs are recognised and that they have a fundamental right for these needs to be met. Their special needs were often overlooked in the past because they were grouped with retarded people. This again emphasises the importance of diagnosis and assessment. As Burt (1987) points out to secure legal rights for persons with autism it is important also to show the similarities between all members of society whether autistic, retarded or normal.

1.14 Right Hemisphere Learning Disabilities

In 1983 Weintraub and Mesulam described children with social and visuospatial problems, and neurological "soft signs" of right hemisphere damage. All these children showed gaze avoidance and most of them use little or no gesture, had monotone voices and were described as shy. These cases were not unlike autism. The authors pointed out that "there is a syndrome of early right hemisphere dysfunction that may be genetically determined and that is associated with introversion, poor social perception, chronic emotional difficulties, inability to display affect, and impairment in visuospatial representation". This picture is reminiscent of autism and Asperger's syndrome. Happe (1994) states that autism was probably not considered because of a narrow conception of autism.

1.15 Schizoid Personality Disorder

Sula Wolff and her colleagues (Wolff and Barlow, 1979; Wolff and Chick, 1980; Wolff and Chess, 1964) studied a group of children which they called schizoid personality disorder who were over-sensitive, emotionally detached, solitary, rigid-obsessive, lacking in empathy and prone to bizarre thoughts. They claimed these were the sort of children Asperger was describing in his 1944 paper. Wolff felt that Asperger's syndrome did not belong within the autistic spectrum but was really part of a group of schizotypal or schizoid disorders.

In 1986 Wolff and Cull described the diagnostic criteria which they felt could distinguish schizoid personality disorder from autism. The characteristics of schizoid personality disorder were:

(1) Solitariness;

(2) Impaired empathy and emotional detachment;

(3) Increased sensitivity, amounting to paranoia;

(4) Unusual styles of communication;

(5) Rigidity of mental set, e.g. single minded pursuit of special interests.

Happe (1994) has pointed out that only increased sensitivity would look out of place in a description of an able autistic child. Wing (1984) makes the point that the schizoid personality diagnosis was vague and while it might include some people with Asperger's syndrome, it also included many with quite different disorders.

Gillberg and Coleman (1992) emphasized the importance of clinical experience and the "gestalt acumen" of the experienced clinician in making the diagnosis of autism. They also point out that "Kanner autism does not have any more validity than any of the other named syndromes on the autistic spectrum" (Waterhouse and Fein, 1989; Wing, 1989; Gillberg, 1992a). Gillberg (1992b) states that eventually it will be possible to distinguish between aetiological and behavioural sub-syndromes, and that the autistic syndromes will be replaced by different syndromes.

Happe (1994) in discussing the issue of differential diagnosis of autism believes that one of the problems with the diagnosis is the narrow conception of autism held by many professionals. She points out that there is pressure to make diagnostic categories progressively narrower particularly to aid research studies. Nevertheless she points out that different manifestations of the same underlying handicap should be grouped together. When we look at autistic spectrum disorders we still have difficulties in establishing which represent distinct disorders.

It is worth also quoting Wing (1993) when she states "the question remains as to whether there is any value in defining particular core autism as distinct from the rest of the continuum. There is as yet, no answer to this. Further research is needed to define subgroups of the spectrum that have some external validity apart from aspects of their observable behaviour. It is possible that Kanner's criteria are to be found mainly in those

who are mildly to moderately retarded and aged between 4 and 12 years of age not because the criteria defines a separate syndrome but because the level of cognitive ability determines the way in which the triad of social impairments is manifested".

Gillberg (1995b) uses the term 'empathy disorder' to cover a broader range of disorders showing some autistic traits and comprising 'autism spectrum disorders' as well as subgroups of other named syndromes (including some cases of elective mutism, DAMP, anorexia nervosa and obsessive compulsive disorder). He describes 'empathy disorder' as a blanket term, similar in some ways to PDD, but covering a broader spectrum of problems with no requirement of 'pervasiveness' or of appearance of first symptoms at a particularly early age in development.

Chapter Two

Epidemiology

Since the first major epidemiologic study of autism was conducted in 1963 by Lotter (1966, 1967) many studies have been conducted in Sweden, France, England, Japan, U.S.A. and other countries (Gillberg, 1995a). Increased prevalence rates have been reported in the past decade (Gillberg, 1992a). There has also been a focus on social class and autism; sibling rank and autism; sex ratios and age of mothers of persons with autism. There is also controversy about the frequency of medical conditions in autism (Steffenburg, 1991; Rutter *et al.*, 1994).

2.1 Epidemiology

The prevalence of autism is clearly going to be influenced by the criteria used to diagnose it. Lotter's (1966) population based study found a "nuclear" autism ('Kanner Autism') rate of 2.0 per 10,000 children and a "non-nuclear" autism rate of 2.5 per 10,000 children; this rate then of 4.5 per 10,000 refers only to numbers found using Lotter's (1966) criteria. Lotter did have a third group comprising 3.3 per 10,000 which contained individuals with some but not all of the characteristics of autism. When the autism or autistic-like conditions are added together Lotter's rate than comes to 7.8 per 10,000 children in the 8 - 10 year old age group.

A number of survey procedures have opted for a case census method. These include Brask (1972) who found a rate of 4.3 per 10,000 of autism and autistic-like conditions. Cialdella and Mamelle (1989) used a similar survey method in France and found a rate of 5.1 per 10,000 for autism and autistic-like conditions combined (with criteria similar to DSM-III) and when broad operational criteria for autism were used they found a rate of 10.8 per 10,000 in the 5 - 9 year old age group. When Hoshino *et al.* (1982) conducted an investigation in care settings they found a rate of 2.3 per 10,000 for ages 0 - 18 years (close to 5.0 per 10,000 for children aged 5 - 9 year olds) using Kanner's criteria for autism. Von Knorring and Hadglof (1993) followed up these patients and found that all except one met DSM-III-R criteria for autism. They found that the majority of symptoms showed stability over time and the individuals had a poor outcome. A few males improved in function and one boy had "grown out of" autism without showing any autistic-like symptoms. This was an unusual finding as one would expect some difficulty with social relating to remain (even if extremely mild). Four out of 38 showed a mildly deteriorating course the majority being females. One person developed schizophrenia. Language and communication tended to improve. The few well functioning individuals with autism were male and the proportion with severe mental retardation was greater in the female group.

In 1984 Gillberg conducted an investigation in care settings using Rutter's criteria for autism and found a rate of 2.0 per 10,000 for nuclear autism. His figure for non-nuclear autism and autistic-like conditions and other childhood psychoses was 1.9 per 10,000 and Asperger's syndrome 0.4 per 10,000 in 4 - 18 year olds.

Steffenburg and Gillberg (1986) conducted an investigation in care settings using DSM-III (APA, 1980) criteria for ages 0 - 9 years and found a rate of 4.7 per 10,000 for nuclear autism and 2.8 for non-nuclear autism and autistic-like conditions and other childhood psychosis and 1.9 per 10,000 for Asperger's syndrome. McCarthy and Fitzgerald *et al.* (1984) found a rate of 4.3 per 10,000 using Rutter's criteria in 8 - 10 year olds. Again all patients were in contact with mental health professionals.

In a major population study of a handicapped population aged under 15 years Wing and Gould (1979) found that the triad of social, language and behavioural impairments in 21 per 10,000 children (including both nuclear and non-nuclear plus other triad cases). There were 35,000 in their population under 15 years. Seventeen (17) children fitted Kanner's and Eisenberg's (1956) two criteria (extreme self isolation and obsessive insistence on the preservation of sameness) and 7 fitted Kanner's original criteria, 4 with Aspergers syndrome and 57 as "other socially impaired". They also showed that the "triad of abnormalities" could be shown in three ways:

a) Aloof - indifferent to others,

b) Passive acceptance of approaches,

c) Active but odd.

Wing (1991) summarises "that 17 of the children (in Wing and Gould's study 1979) fitted Kanner's and Eisenberg's (1976) two criteria for autism but only 7 out of 17 fitted Kanner's (1943) original five criteria".

Kanner and Eisenberg's (1956) two criteria which they regarded as of primary importance and sufficient for a diagnosis of autism were extreme self isolation and obsessive insistence on the preservation of sameness. Wing (1991) went on to state "that although it was possible to identify the diagnostic criteria when present in typical form, for every item there were problems delimitating the borderline. Thirdly, the criteria for different syndromes overlap so much that some children could be given two or more diagnoses. Fourthly, many children had mixtures of features from different syndromes, and could not be fitted precisely into any diagnostic category. The more narrowly the criteria were defined the fewer children that could be included".

Gillberg *et al.* (1986) confirmed Wing and Gould's findings in a study of all 13 to 17 year old children with mental retardation in Goteborg. In Gillberg's *et al.* (1986) study 20 per 10,000 children had a combination of mental retardation and "the triad" (including nuclear and non-nuclear autism).

One of the effects of the differences in criteria for autism is to alter the I.Q. range of the children diagnosed as autistic (Wing, 1987). Kanner's insistence on good manipulative or rote memory skills excludes many severely retarded children and virtually all those who are profoundly retarded. The criteria for Asperger's syndrome used by Wing (1981a) ensure that only people in the more able end of the autistic continuum are included, whereas Wing and Gould's (1979) definition of the whole autistic continuum includes all intelligence levels from profound retardation to average and above. Wing (1987) defines the autistic continuum or spectrum as more or less equivalent to the group of pervasive developmental disorders as described in DSM-III-R (APA, 1987) a classification system she had a major input into.

2.2 Increased Prevalence of Autism

Gillberg (1992a) pointed out that during the past decade the prevalence of autism as reported by a number of researchers has shown an increase (Bohman *et al.*, 1983; Bryson *et al.*, 1988; Tanoue, Oda *et al.*, 1988; Cialdella and Mamelle, 1989; Sugiyama and Abe, 1989; Logdahl, 1989). The rates of autistic and autistic-like conditions were 10.1 per 10,000 (Bryson *et al.*, 1988), 13.8 per 10,000 (Tanoue *et al.*, 1988); 13.0 per 10,000 (Sugiyama and Abe, 1989); 11.5 per 10,000 (Gillberg *et al.*, 1991). Gillberg (1995a) described an increase from 4.0 per 10,000 in 1984 to 11.5 per 10,000 in 1991 in his studies. This increase was put down to better detection and to new cases born to immigrant parents.

The prevalence of Asperger Syndrome is likely to be at least 3/1000 children born but could be higher according to Gillberg and Gillberg (1989). Gillberg, Schaumann, Gillberg (1995) found that the prevalence for autistic disorder in Goteborg children born to mothers who were born in Uganda was 15% which is almost 200 times higher than in the general population of children.

Bryson *et al.* (1988) point out that case registers supplemented by screening among professionals underestimates prevalence of autism Bryson *et al.* (1988) got a much increased number of children returned as problems (12.9%) compared with 2.9% by Lotter (1966) because Bryson *et al.* asked teachers to rate 19 items reflecting social, language and repetitive behaviour while Lotter (1966) provided teachers with examples of children of "interest".

Bryson *et al.* (1988) also suggested that their higher prevalence may also reflect the use of diagnostic criteria which emphasize areas of dysfunction rather than specific maladaptive behaviours. They suggested that Lotter's (1966) case selection was based on a total score of autistic behaviours, each rated as to severity. Children selected by such criteria may well, but would not necessarily, show impairment in all three functional domains. They also stated that their population could include children whose total scores might not have met Lotter's cut off. While Bryson *et al.* (1988) criteria were broad criteria (Denckla, 1986; Bryson *et al.*, 1988) they state that it remains an empirical question whether they differ in significant ways from those identified in previous epidemiological studies. The increased prevalence found by Bryson *et al.* (1988) could not be accounted for by an excess of asocial severely retarded individuals (Cf. Steffenburg and Gillberg, 1986).

Deb and Prasad (1994) in a study of autistic disorder among children with a learning disability found that "14.3% of children with learning disability fulfilled the diagnostic criteria for autistic disorder. This gave a 9 per 10,000 minimum prevalence of autistic disorder among all school children in the Grampian region". It is interesting to note that Scragg and Shah (1994) found a prevalence of 1.5% (0.6% to 3.3%, 95% CI.). When they added equivocal cases this increased the prevalence of Asperger's Syndrome in Broadmoor (Secure) Hospital in the United Kingdom to 2.3%.

The first question is whether there is a real increase or just an increase due to changes in diagnostic criteria by the broader criteria of DSM-III-R (A.P.A., 1987). Gillberg (1992a) points out "this could not account for the high prevalence in published epidemiological studies since they did not use this diagnosis at all. Nevertheless, gradually looser autism concepts could have contributed to the steady prevalence rise". He goes on to state that "the rate of autism (and the rate of autistic-like conditions) associated with mild mental retardation has remained at almost exactly the same level throughout the whole period

(Goteborg studies); autism associated with immigrant status, severe mental retardation and near normal or normal intelligence on the other hand have all shown an increase" . . the rate of typical (Kanner autism) in Gotenburg appears to be stable". It seems possible that with Wing and Gould's (1979) examination of handicapped populations for autism may have been a factor in the reported increase in autism. Gillberg (1992a) believes the rates of autism among severely handicapped groups now may be close to the true prevalence in that population. He also states that the increase among "those with autism with severe mental retardation and those with relatively high-functioning autism is likely to be apparent rather than real and brought about in better detection".

Gillberg (1995a) points out that two U.S. studies showed low rates since 1985 (Burd *et al.* 1987; Ritvo *et al.*, 1989) and he noted the problems of population based studies in the USA with their mobile populations and health care not being provided in a population - comprehensive fashion. Gillberg (1995a) points out that the "mean rate of reported autism in the prevalence studies published after 1985 was 11.8 per 10,000" allowing for Burd *et al.* (1987) and Ritvo *et al.* (1989) being treated separately.

Gillberg (1995a) indicated population based studies of autism which had "better coverage, more thorough screening" and used operationalized criteria of diagnosis. The following are the ones he identified as well as showing the rate of autism per 10,000 children born (age specific).

Table 2.1: Population Based Studies of Autism

Lotter[a] (1966)	4.5 / 10,000	in 8 - 10 year olds.
Brask (1972)	4.3 / 10,000	in 2 - 14 year olds.
Wing and Gould[a] (1979)	4.9 / 10,000	in 3 - 17 year olds.
Hoshino *et al.* (1982)	5.0 / 10,000	in 4 - 10 year olds.
Ishii and Takahashi (1982)	16.0 / 10,000	in 6 - 12 year olds.
Bohman[a] *et al.* (1983)	6.1 / 10,000	in 0 - 20 year olds.
Gillberg[a] (1984)	4.0 / 10,000	in 4 - 18 year olds.
Steffenburg and Gillberg[b] (1986)	7.5 / 10,000	in 0 - 10 year olds.
Burd *et al.* (1987)	3.3 / 10,000	in 2 - 18 year olds.
Matsuishi *et al.* (1987)	15.5 / 10,000	in 4 - 12 year olds.
Tanoue *et al.* (1988)	13.8 / 10,000	in 7 year olds.
Bryson *et al.* (1988)	10.1 / 10,000	in 6 - 14 year olds.
Cialdella and Mamelle (1989)	10.8 / 10,000	in 5 - 9 year olds.
Sugiyama and Abe (1989)	13.0 / 10,000	in 3 - 5 year olds.
Ritvo *et al.* (1989)	4.0 / 10,000	in 8 - 12 year olds.
Gillberg *et al.* (1991)[c]	11.6 / 10,000	in 4 - 13 year olds.

Footnote: Gillberg points that in those rates marked [a] about half this proportion were attributable to 'nuclear' Kanner autism. He also pointed out that all 'typical' cases met DSM-III and Kanner criteria for autism and all but one of these met Rutter criteria marked[b]. Finally he pointed out that "all 'typical' cases met DSM-III-R criteria for autism and all but one of these also met DSM-III criteria" and was marked[c] in the above table.

Gillberg *et al.* (1982) found that 1.2% of all 7 year olds had deficits in attention, motor control and perception (DAMP). He found that those with severe DAMP quite often exhibit social impairments, semantic pragmatic problems and restricted stereotyped - repetitive - obsessive behavioural patterns of a milder variant, but of the same type as those encountered in autism (Gillberg, 1983). Gillberg (1992a) states that there are no clear boundaries between autism, Asperger's syndrome, semantic pragmatic disorders and DAMP.

Cox, Baron-Cohen *et al.* (1995) excluded very low functioning children but still have one of the highest rates in the whole literature. Gillberg (1996) pointed out that autistic disorders occurred in 1 / 1,000 children whether diagnosed by DSM-III or DSM-III-R and that most remain handicapped throughout life. Gillberg (1996) pointed out that Asperger's syndrome occurred in 3 - 7 / 1,000 children of school age, and that the prevalence of high functioning autism is likely to be under 0.5 / 1,000 children. Wing (1996b) discusses a "tentative estimate for the prevalence of autistic spectrum disorders of 91/10,000 children aged under 16 of any level of I.Q.".

2.3 Sibling Rank

Gillberg and Coleman (1992) state that there is no clear consensus with regard to rank order and autism. They favoured a position of Tsai and Stewart (1983) that more first and late born (fourth or later) children are autistic. Jones and Szatmari (1988) have suggested that parents who have an autistic child tend to have no more children or if they do to limit to one more. It is interesting that Despert (1951) Kanner (1954) and Rimland (1964) suggested a high number of first born autistic children but later reports Wing (1980) and Lotter (1967) demonstrated conflicting results.

2.4 Social Class

Kanner (1943) and Asperger (1944) noted the high social class of their families with autistic children. This became generally accepted. The only major epidemiologic study which showed some evidence of social class bias was Lotter's (1966). When the diagnosis of autism was first recognised it is likely that it was more middle class parents who brought their children forward for diagnosis (Wing, 1980; Gillberg and Schaumann, 1982). Gillberg (1996) and states that looking at the whole autism group there is no correlation with social class. Gillberg (1996) goes on to say "that if there is a slight bias in high functioning autism this could be due to the selection in itself that you are looking at the most intelligent group of a disorder and perhaps that is what you will find in terms of social class".

2.5 Sex Ratios

The sex differences in instances of autism has been documented repeatedly in both epidemiologic (Lotter, 1966; Treffert, 1970; Wing, 1981c) and clinic based studies (Baird and August, 1985; Lord and Schopler, 1985; Rutter and Lockyer, 1967; Tsai and Beisler, 1983). There has been considerable focus on sex ratios at different points along the I.Q. spectrum with evidence that the excess of autistic females is weighted towards the lower end of the I.Q. spectrum (Tsai, Stewart, August 1981; Wing, 1981c).

All the sex ratios that have been found in previous Scandinavian studies have ranged between 1.9:1 pooled male:female ratio in 5 Scandinavian studies, (Gillberg, 1995a) and 16:1 (Wing and Gould, 1979) that is male to female ratio.

Gillberg (1995a) points out that European studies show a lower male:female ratio (2.2:1) when compared to the pooled Canadian, U.S. and Japanese studies (4.5:1). Gillberg (1995a) suggests that the particularly high rates of male to female ratio in Japanese studies 5.4 : 1 (male to female) when compared to Scandinavian studies could "not be due to high rates of mental retardation in Scandinavian studies since the rate of I.Q. < 70 was the same in these studies as in studies from other areas". Wing (1993) pointed out that "the exceptionally high ratio in Camberwell (16:1) was probably a chance finding due to the small number of autistic children identified". Gillberg (1992a) states that it does appear that the ratio might be higher in typical "Kanner autism" as compared to "almost nuclear Kanner" cases. Kopp and Gillberg (1992) have suggested that girls could have a slightly different behavioural phenotype than boys and that in girls a "combination of superficially uncharacteristic social deficits and learning problems may sometimes qualify for a diagnosis of autism" (Gillberg, 1995a). They also point out that girls could have repetitive play patterns involving dolls and soft objectives rather than spinning objects such as wheels and other hard objects which are "more likely to be readily associated with the syndrome of autism" (Gillberg, 1995a). Frith (1989) points out that "the excess of boys found consistently in all studies and the scarcity of girls at the middle and higher ability levels are typical "clues" to the biological origin of autism. Frith (1989) points out that autistic girls were more seriously impaired on almost every ability tested than the autistic boys e.g. lower non-verbal I.Q.; poorer daily living skills; performing poorer on language and perceptual tests. Frith (1989) makes the important point that in terms of play or affect or the ability to relate performance was the same for boys and girls. She concluded that girls were not more "autistic" than boys but had more additional severe problems.

It has to be noted that very small samples yielded in epidemiological studies make these results difficult to interpret (Lord and Schopler, 1987). These differences in the incidence of autism for males and females have been used in generating hypothesis about polygenic transmission of autism in families (DiLavore and Lord, 1991; Tsai *et al.*, 1981). Volkmar and Szatmari's (1991) study compared autistic males and females on the Autism Behaviour Checklist (Krug *et al.*, 1980), age of onset, and ratings of ICD-10 draft (WHO, 1987). They found no significant differences between males and females that were not related to I.Q. For example females may be more strongly affected by the autism gene or there may be genetic heterogeneity, with more "mild" forms (incomplete penetrate) of this disorder being X linked and hence more common in boys. Lord *et al.* (1982) found that significant sex differences in unusual behaviours were usually accounted for by significantly lower non-verbal intelligence in females than males. McLennan *et al.* (1993) stated that "There is no evidence that females are generally more 'autistic' than males". They found that males were rated to be more severely autistic than females on several measures of early social development.

Nevertheless the hypothesis of multifactorial inheritance predicts that the less frequently affected sex (female) is more severely affected with whatever the defining characteristics of autism are (Tsai *et al.*, 1981). The reason for the lower ratio of 1.5:1 in a twin study Steffenburg *et al.* (1989) is uncertain. Gillberg and Coleman (1992) points out that in Asperger's syndrome the boy: girl ratios are higher. Gillberg and Coleman (1992) have

suggested that whereas "boys are (genetically?) much more prone to developing autism, more severe brain damage would be required for the development of autism in girls". Kopp and Gillberg (1992) suggest that the autistic phenotype might be different in girls compared to boys. They described girls whose social impairment tended towards "clinging" to other people "imitating their speech and movements without a deeper understanding of the silent laws of ordinary social interaction" and an inability to understand the emotional content of facial expressions as well as treating people as objects. Wing (1981c) suggested that autism may be a pathological exaggeration of the traits in men generally. Kopp and Gillberg (1992) hypothesized that the core deficit in autism could be more common in females than previously believed and that there has been an over reliance on the "male prototype of autism". Kopp and Gillberg (1992) conclude that it is possible "that the strong male preponderance in autism might be shown to be just another autism myth?".

Gillberg (1996) points out that the autism increase of males over females is probably not as great as was once believed. The population studied suggest that it is 2 - 3 to 1 rather than 5:1.

Rutter *et al.* (1993) stated that a multigene model leads to the expectation that the loading should be higher in the case of females because they are less often affected than males. They point out that the data on this point are somewhat contradictory; though several studies suggest that there may be a greater loading in families of female autistic subjects. They also state that the statistical power to detect sex differences was low in all studies and the matter remains unresolved (August *et al.*, 1981; Bolton *et al.*, 1994; Lord *et al.*, 1991; Ritvo *et al.*, 1989; Tsai and Beisler, 1983; Tsai and Stewart *et al.*, 1981). Clearly the matter is far from resolved and will require further genetic studies to increase our understanding of it.

2.6 Maternal Age

Gillberg (1980) showed a statistically significant increase in mean maternal age in persons with autism. The literature is inconsistent on this point. There have been a number of reports of increased maternal age (Arajarvi *et al.*, 1964; Treffert, 1970; Finegan and Quarrington, 1979). Others have found no increase in maternal age in persons with autism (Lotter, 1966; Torey *et al.*, 1975; Wiedel and Coleman, 1976; Steinhausen *et al.*, 1986). It is possible these differences could be explained by diagnostic differences.

Chapter Three

The Individual, Family, External World and Services

Autism has major but variable impacts on the individual, family, the relationships between these factors, the external world and for services. It is critical that the implications of autism is thought of from the perspective of the life cycle and the changing needs and problems of the person with autism over this period. There is also considerable impact on the family, marriage, fathers and mothers, on the individual as well as their siblings. The impact is not always negative. Support networks are of critical importance. The issue of how families cope is a critical if very complex issue, as is the relationship between coping and resources. All these factors have major implications for services.

3.1 The Life Cycle of the Person with Autism

Pre-school Years

If abnormalities are recognised during the first year and sometimes they are, the greatest need at this stage is for diagnosis and assessment. While some children can be remarkably quiet during the first year others can be restless, irritable and difficult to care for. Indeed some parents at this stage never have a peaceful night and indeed suffer from chronic exhaustion.

As Wing (1994) points out social isolation and social peculiarity can be at their worst between 2 and 5 years. Children at this age can be "challenging" because they find the human world so confusing. As DeMyer (1979a) reported parents found the pre-school years to be the most difficult for them and for their children. Seventy eight per cent (78%) of the children that DeMyer (1979a) studied had the greatest difficulties in the areas of speech, social relations and general disposition between 2 and 4 years of age. These children show problems with physical aggression, eating problems, poor play skills, lack of initiative, sleep problems, tantrums and toileting problems. These problems require behavioural management techniques e.g. attempts to reduce aggressive behaviour in pre-schoolers with autism and focussing on increasing their understanding of their environment through the use of predictable routines or visual cues. These children are often confused about people and what they want and are frustrated because of their inability to express themselves. A pre-schooler with autism may get aggressive when one activity is ending and it is time to do something else. It is important to give the child a way to anticipate what is coming next, such as showing a ball to indicate it is time to go outside, and then the child's confusion and subsequent aggressive behaviour is likely to diminish (Van Bourgondien, 1993).

Five to Ten Years

During the school years, many of the behaviours that were most disturbing in the pre-school period will tend to abate (Wing, 1994). There is a general tendency of lessening of

the challenging behaviour of the pre-school child. At the same time ritualistic and compulsive behaviour can persist at this period with resistance to change and abnormal preoccupations.

Adolescence / Adulthood

Mesibov *et al.* (1983) points out that autistic children generally improve in specific skill areas during adolescence. He points out that activity levels generally decreases, behaviour becomes more manageable, self-help skills improve, speech and language show continual development. There can of course be the onset of seizures and aggressive and self injurious behaviours can become more problematic. Rutter (1970) found fair to good outcomes in only 17% of their autistic adolescents. Of course the growth of the child is another significant issue where mildly unpleasant behaviours like pushing or shoving in a small child can become destructive and dangerous in a large adolescent. Unfortunately in adolescents the improvement in skills and behaviour is unable to keep pace with the increasing demands that society places upon an individual as he or she approaches adulthood. There is some evidence that echolalia is often outgrown by the time adolescence is reached (Rutter *et al.*, 1977). The issue of sexuality is also a significant issue in adolescents. Communities fear the sexuality of autistic people and advocates want an assurance that autistic people are allowed to exercise their sexual rights. Depression which can appear in adolescence (Wing and Wing, 1980) may be associated with dawning awareness of the implications of the autistic handicap and failures in personal relationships, especially with the opposite sex. Treatment will include medication and counselling. Psychosis of the adult type with delusions and hallucinations, including typical schizophrenia, have been reported (Wolff and Chick, 1980).

It is clear that changes can occur in the presentation of autism between childhood and adulthood. Wing (1991), as already described has pointed out that a child may look typically Kanner-type autistic in infancy and yet develop into a more Asperger's syndrome-like adolescent.

Gillberg and Coleman (1992) point out that the onset of epilepsy, deterioration, aggravation of symptoms and additional psychiatric problems are the most common complications that adolescents with autism face. Kanner (1973) has pointed out that a small group of children do improve during the teenage period. Gillberg and Steffenburg (1987) in a follow up study showed that 22% showed deterioration that is 12% of the males and 50% of the female group. The author (M.F.) has often observed an increase in self destructiveness and aggressiveness in adolescents with autism.

Gillberg and Coleman (1992) point out that a small portion of persons with autism develop into normal (or "near normal"), or sometimes highly original though not psychiatrically ill grown ups. In Rutter's (1970) follow up study of patients who were between 15 and 29 years old almost half were in long stay mental sub-normality or mental hospitals, and rather fewer than 20% were in employment. In half of the autistic patients interpersonal relationships had tended to improve as the children got older. A few children became somewhat outgoing in personality, although "remaining shallow in affect and lacking in empathy", but more usually the children were reserved, without social "know-how" and seemingly unaware of their feelings of others. Only two had close

friends of their own and only one had heterosexual friendships. About half of the cases were without speech when adolescent, and those who talked did so in a monotonous flat delivery, with a pedantic mode of expression that lacked the normal to and fro of conversation. Lord (1984) pointed out that particular autistic individuals may begin as "aloof" but later become "passive" or even "active but odd" in their social manner.

3.2 The Family: Needs, Stress and Coping

Families who have a person with autism as a member experience increased levels of burden in many areas (Schopler and Mesibov, 1984). They experience increased levels of stress (and are occasionally strengthened by the experience). There is disruption of routine family activities and family leisure; evidence of increased financial burden as well as having an effect on the mental and physical health of family members. These families experience many different needs of professional and voluntary services. As Cutler and Kozloff (1987) point out they need adequate and appropriate education for their children with autism and this means an extended school day and year round education programmes in schools close to home that offer appropriate supports and services provided by personnel knowledgeable about autism. Parents want their children to be particularly helped with communication and functional living skills. Cutler and Kozloff (1987) go on to point out that they also need respite care even when parents have adequate education for their children with autism. Parents provide most of the care for their autistic children. They need planned relief from the daily care to allow themselves time with their other children, personal time to maintain special friendships, sleep, and otherwise to renew themselves. They also need crisis care for family emergencies. They want to be helped to be more effective in teaching and managing their children over the life cycle. Cutler (1981) points out that they need basic advocacy-system skills as at some point in their career parents begin to understand that they require special knowledge of their rights and of the operation of systems upon which they will or do depend for services. They need an array of supports including peer support groups, case management and information in accessing financial help from various government departments.

Parents want services provided by people who understand their childrens needs and who understand autism as well as people who value children with autism. Moreno (1992) suggests that professionals do not say "I know just how you feel" because she says while a professional can empathize with her they are not experiencing this process themselves. She recommends professionals to include their autistic loved ones in their social gatherings or outings whenever appropriate. She also recommends that professionals do not say "you must be a very wonderful person for God to have chosen you to have this child". She recommends that professionals do not offer unsolicited advice and also not to say "but all teenagers - toddlers - young men do that or have a problem with that". She also recommends that the professional does not try to cheer a parent by saying "you don't know for sure that the autistic loved one won't ever be able to . . .". She points out that a professional must realise that parenting any person with autism, regardless of functioning level, is a very challenging experience.

There is some evidence that professional people who are specialized in the diagnosis and treatment of autism are more effective in relating to parents. Parents feel that they seem to understand what autism is about and were more realistic and useful to parents in the

advice they gave than in the advice received from non-specialists. Of course non-specialists are the most common professionals that families will meet. In the past (Sullivan, 1976) reported less services for adolescents with autism as compared to children with autism. There was a lack of vocational training, alternative community placements, and recreational programmes for adolescent autistic children. Clinical experience suggests that this is changing now.

Henderson *et al.* (1992) showed statistically that features of service delivery systems may be important in promoting family adjustment. It is interesting as well that Holmes and Carr (1991) found that adult training centres were perceived positively by 85% of parents of persons with autism.

Bristol (1979) showed that the number of coping problems reported by mothers was significantly related to both the characteristics of the autistic children themselves and the adequacy of programming available to them. It appeared that families with "easier", less dependent children and adequate services were able to cope more successfully (Bristol and Schopler, 1983). Henderson and Vandenberg (1992) also found that the severity of the child's disorder was a significant factor influencing adjustment in the family to an autistic child. Sloper *et al.* (1991) found that for mothers childrens levels of behaviour problems, excitability and self-sufficiency were significantly related to mothers level of stress and satisfaction with life where there was a Down's syndrome child.

3.3 Mothers

A number of investigators have found that mothers of mentally handicapped children do experience high levels of stress (Beckman, 1983; Bradshaw and Lawton, 1978). Beckman (1983) concluded that the only demographic characteristic associated with the amount of stress experienced by mothers was the number of parents in the home, with single mothers experiencing more stress.

Bristol and Schopler (1983) noted that some mothers of older children had "burned out". They pointed out that the parents had done as much as they could and if the child was not making progress and good services were not available that the mothers felt they could no longer justify sacrificing their lives for the autistic child. If the child was not doing well the mother had the sense that her sacrifices had been in vain. Cox, Rutter *et al.* (1975) in a study of mothers of autistic and dysphasic children found that almost a third of the mothers in these families of handicapped children reported instances of depression in response to stress associated with the birth or presence of the handicapped child in the family. DeMyer and Goldberg (1983) points out that mothers emotional and mental health was worsened by the stress and anxieties of rearing, treating, and educating an autistic child. DeMyer (1979a) reported that 33% of the mothers of pre-school autistic children had definite mild reactive depressions and that all parents felt anxious and upset because of the "nerve wracking" behaviours of their autistic child. DeMyer (1979a) also noted that before the autistic child's birth there was no greater incidence of depression in the mothers than in a matched control group. Those mothers who had given up their child to residential care retained a measure of sadness over seeing their child enter the "shadowy world of a mental institution". At the same time some mothers found their emotional life enriched as a consequence of having an autistic child.

The mothers of persons with autism described varied experiences which they found burdensome. Indeed these burdens can continue throughout the life cycle. The normative life events e.g. going to school, 21st birthday parties etc. can be periods of great stress for families of persons with autism. These are the times when the various handicaps can be thrown into sharp relief for the parents (Wikler *et al.*, 1981).

3.4 Fathers

Although most research has been conducted with mothers, reviews of research on fathers of handicapped children (Bristol and Gallagher, 1982; DeMyer, 1979a; Price-Bonham and Addison, 1978) reveal that significant emotional and financial strains are experienced by fathers, who often lack outlets to deal with such stress or to contribute to the child's progress. Sloper *et al.* (1991) compared mothers' and fathers' Malaise scores (Rutter *et al.*, 1981) and found that the findings supported other investigations of families of younger children (Goldberg *et al.*, 1986), in showing fewer symptoms of stress for fathers of children with disabilities than for mothers.

As Holmes and Carr (1991) point out one might expect that fathers would give more help when the handicapped child became an adult, partly because size might make it difficult for the mother to cope physically and partly because fathers, through retirement, would have more time at home but there are conflicting findings from the few studies that had been completed in this area. Bayley (1973) in his study of 54 Sheffield families found that 39% of the fathers gave "much help" and were considered an integral part in the coping structure of the family. Grant (1986) showed that personal care, household chores, and minding were the primary responsibility of the mother. Hirst (1985) in a study of young adults with disabilities noted that only a minority of fathers were significantly involved with daily physical care. In Ayer and Alaszewski's (1984) study, unemployed fathers of handicapped children participated no more in caring than did those who were employed although Wilkin (1979) observed the opposite. Cooke and Lawton (1984) found fathers in manual classes more helpful whereas Ayer and Alaszewski (1984) found the opposite. Hirst (1985) found no effect on participation by social class or employment but did discover that fathers of young men were more likely to help with physical care than fathers of young women.

Holmes and Carr (1991) found that the brunt of caring falls upon mothers and that fathers were most likely to help with the supervision of the handicapped person rather than participating in physical care or household tasks. Fathers did the more traditional male tasks like repairs, decorating, etc. Holmes and Carr (1991) found that non-working fathers were more highly participant.

Harris (1994) points out that these personal qualities appear to influence individuals perception of the stressor. Gill and Harris' (1991) studied hardiness in 60 mothers with children with autism and found that women with higher hardiness scores were less likely to report somatic complaints and these women who scored higher on the commitment subscale of the hardiness measure were least likely to voice symptoms of depression. In another study of mothers of children with autism Gill (1990) found that hardiness and social support were effective buffers to stress for these women and women with hardier attitudes also viewed themselves as having more supportive networks.

3.5 Siblings

DeMyer and Goldberg (1983) described clinical vignettes where mothers state that it was "impossible for any of us to have a life of our own". Another mother admitted that in hindsight her other children were extremely negatively effected before the autistic adolescent was hospitalized at age 17 years. At the same time about one third of parents believed the siblings had been strengthened by the experience of having an autistic sibling and that they had achieved empathy and care for all unfortunate people earlier and to a greater degree than other youngsters.

Looking at the results of studies of siblings of handicapped children reveals mixed outcomes. Some siblings suffer from emotional and behavioural disorders (Cohen, 1962; Farber, 1959; Gath, 1974; Schwirian, 1976). The pervasive nature of this stress is highlighted by studies which indicate that the negative effects on siblings may continue into adult life (Cleveland and Miller, 1977; Grossman, 1972) and not merely a temporary reaction to increased child rearing demands posed by the handicapped child (Bristol and Schopler, 1983). As DeMyer and Goldberg (1983) point out siblings can suffer burn out and move to distant cities or alternatively submerge their own needs until some urge within propels them to independent expression. Carr (1975) in her study of Down's syndrome children found that one third of the mothers reported that they relied on the other, mainly grown up children for help and support. Dupont (1980) said that in one third of families she studied the siblings helped with child care and in two thirds they helped supervise the handicapped child. Wilkin (1979) noted that most help came from siblings, mainly female, in the 12 - 16 age range, and that only 18% of siblings who had left home gave any help at all whereas Bayley (1973) found siblings living away from home contributed more than those still at home. Holmes and Carr (1991) found that siblings living at home contributed to the caring process. Although they did not appear over burdened with caring they were recognised as a source of help. The siblings who had left home offered very little in the way of help; just one third occasionally minded the subject.

Gath (1973) compared children with siblings with Down's syndrome to siblings of non-handicapped children on the basis of behavioural rating scales completed by parents and teachers. Differences found were due to a significant increase in "antisocial disorder" in older sisters of children with Down's syndrome. Among the children most at risk were those of older mothers, those from larger families and those from social classes 4 & 5. Grossman (1972) also interviewed adult siblings and judged 45% to have benefited from their experience. These benefits include an increase in altruistic concern and tolerance towards others. Byrne and Cunningham (1985) point out that the results in combination seem to suggest that effects of siblings of mentally handicapped children cannot be described solely in terms of stress and psychological impairment. It appeared that older sisters do appear to be the most vulnerable, due perhaps to extra child care, house work and other responsibilities assumed.

As Gold (1993) points out the literature shows both positive and negative effects on siblings of living with a child with autism (DeMyer, 1979b, Mates, 1990; McHale *et al.*, 1986; Sullivan, 1979). Gillberg (1995b) points out that even though a minority of siblings may be severely distraught by having a handicapped brother or sister, "there are also those who will attest to the experience of having a handicapped sibling as rewarding" (Bagenholm and Gillberg, 1991). Nora Gold (1993) points out that in general although

these siblings do not overall have more adjustment problems than other children, they are predisposed to risk in the presence of certain factors. These factors include an increased severity of disability (Farber, 1959; Gianndrea, 1984; Lobato, 1983; McHale *et al.*, 1984; Vadasy *et al.*, 1984). There is also evidence that disabilities which are ambiguous or undefined were associated with poorer sibling outcome particularly in families of higher socio-economic status (McHale *et al.*, 1984). Bristol (1984) has shown that this ambiguity is associated with autism. As far as age of the child with autism is concerned studies are not conclusive with McHale *et al.* (1984) showing an increased difficulty and stress for the sibling as the disabled child grows older whereas Gianndrea (1984) showed the opposite. Lobato *et al.* (1987) found that mothers of handicapped children reported that preschool sisters had more responsibility for child care and household tasks than brothers had. Breslau (1982) showed that younger brothers of disabled children showed more psychological impairment than older brothers, but older sisters showed more impairment than younger ones. Gath (1974) and McHale *et al.*, (1984) found that siblings in larger families adjusted better than those in smaller families unless the family was financially stressed or unless the sibling was the eldest or middle born girl (Gath, 1974; Lobato, 1983). McHale *et al.* (1984) has shown that siblings of disabled children make a better adjustment if the parents have a good marital relationship. Gath (1978) has shown that siblings tend to echo and identify with their parents feelings and attitudes. Trevino (1979) has shown that parental shame, guilt, anxiety or acceptance may be more critical influences on the sibling than the objective characteristics of the disabled child. Gold (1993) found that sisters of autistic boys did not do significantly more domestic work. She found "no statistically significant gender differences". She found that siblings of autistic boys scored significantly higher on depression than a comparison group but not on problems of social adjustment.

3.6 Marital Relationships

Byrne and Cunningham (1985) point out that there is no conclusive proof that having a mentally handicapped child would place great strain upon the parents marital relationship. Gath (1977) based upon the results of an interview study rated significantly more marriages as "poor" among the parents of children with Down's syndrome than among parents of non-handicapped children. However, although all negative measures of the marital relationship of the parents of children with Down's syndrome were higher than in the control group, positive measures were also higher in this group. An equal number of marriages were rated as good in both groups. Waisbren (1980) found no differences using the Locke Wallace Marital Adjustment Inventory (Locke and Wallace, 1959) between parents of mentally handicapped and parents of non-handicapped children. Friedrich and Friedrich (1981) found that parents of mentally handicapped children experienced significantly less marital satisfaction that control parents. Byrne and Cunningham (1985) speculate that marital satisfaction made this decrease disproportionately over time in families with mentally handicapped children. Farber (1959) examined the effects of having a severely mentally handicapped child on family integration and found that the outcome was more closely related to marital integration prior to the presence of the child than to any influence of the child. Gath (1978) also reached this conclusion.

DeMyer and Goldberg (1983) point out that marital relationships are probably more strained early in the life of the autistic child. DeMyer (1979a) found innumerable daily

tensions that parents said "put nerves on edge" and set off marital quarrelling and diminished sexual interest, particularly in mothers. DeMyer and Goldberg (1983) point out that if parents do not learn early in the life of their autistic child to be supportive of each other, divorce can result. Several mothers felt that placing the autistic child in residential care either saved their marriage or greatly improved it. Most couples state that having an autistic child has a major effect on their marriage, in some cases building a stronger bond but in other cases driving the couples further apart.

3.7 Coping and Resources

Byrne and Cunningham (1985) define coping as behaviours, cognitions or perceptions directed at the resolution or mitigation of potentially stressful life events. Coping is a very active process which includes not only what the family with an autistic person receives but also actually what they do to deal with the stressful situations that they find themselves in (McCubbin *et al.*, 1980).

3.8 Coping Strategies

Cohen and Lazarus (1979) have pointed out that there at least two distinct types of coping strategies. The first one is described as instrumental where the family attempt to change the stressful situation directly, and the second one is described as palliative where the family tends to minimize, tolerate, or ignore the stressful situation.

The families use instrumental coping strategies when they learn new information and skills to deal with the person in the family with autism. Another instrumental strategy would be advocating for new services. Schopler, Mesibov, De Vellis, Short (1981) have used an instrumental coping strategy with parents when they train them to be co-therapists for their family members with autism and in this way they have improved parents teaching skills, reducing childrens inappropriate behaviours, increasing functional skills and preventing unnecessary institutionalization.

Hill (1949, 1958) identified a family coping strategy based on parental beliefs which focussed on the families subjective definitions or beliefs about the stressful event e.g. emphasizing that they are not responsible for causing their childs autism. Crnic *et al.* (1983) and Turnbull *et al.* (1984) point out that the families beliefs and perceptions about mental handicap and related issues may be central to the coping strategies they evolve and in turn may be modified by the particular strategies used. Mothers of mentally handicapped children have been found to have more positive attitudes about handicap than did a group of mothers of similar socioeconomic status and education (Watson and Midlarsky, 1978).

In order for families to engage in palliative actions such as developing new interests and activities such as hobbies or a career will require increased access to services such as baby sitting and child care.

3.9 Coping Patterns

Mink *et al.* (1983) studied coping patterns evolved by 115 families of mentally handicapped children. They found 5 distinctive clusters of families. These were:

(1) Cohesive and harmonious.

(2) Control-orientated and somewhat unharmonious.

(3) Low disclosure and unharmonious.

(4) Child oriented and expressive.

(5) Disadvantaged and low morale.

They noted that the cohesive harmonious families demonstrated low levels of conflict and high levels of moral/religious emphasis. On the other hand the child oriented, expressive families showed high levels of pride, affection and warmth towards the child and did not use physical punishment. They assessed the childs abilities realistically. On the other hand children from control-oriented families showed low levels of adaptive behaviour. The disadvantaged families with low morale were demoralised and under significant financial stress. Finally the low disclosure, unharmonious families showed an unwillingness to disclose information. Byrne and Cunningham (1985) suggest that the differences between the families were due to differences in resources i.e. social supports and beliefs and perceptions. They also point out that the idea of coping as a single continuum with some families coping well and others not so well is an unwarranted assumption as coping behaviour may vary depending on the families changing situation and resources.

Volkman *et al.* (1979) identified potential resources as health and energy of individual family members, family members problem solving skills, family members perceptions and definitions of their situation and relationships within the family as well as the families social and support networks. Bristol and Schopler (1983) point out that successful families of autistic adolescents describe themselves as "close-knit", "able to role with the punches", and able to adjust as the childs needs change. They seemed to be able to laugh and have a sense of humour. McCubbin *et al.* (1980) points out that the more intelligent and better educated parents may be able to understand the stress of having a person with autism better and therefore be better able to develop more satisfactory problem-solving skills; other personal resources of these parents would be good self esteem and a sense of having some control over their lives. This has been shown to influence a families ability to cope with stress (McCubbin, 1979; Pearlin and Schooler, 1978). Other internal resources of the family system would include cohesion and adaptability (McCubbin *et al.* 1980). Pratt (1976) has described families who cope with stressful events as those who are characterized by flexible role relationships and shared power. While the word coping certainly makes clinical sense it is construct that has come under considerable scrutiny. Garmezy (1990) points out that coping as a construct leaves much to be desired. He states that its limitations reside in the quality of the instruments for measuring coping, their lack of psychometric properties and the questionable assumption of transitional generalizations that can be drawn from test responses to hypothetical or even actual situations. The following Figure 3.1 shows a possible model of coping and non-coping. The model highlights the importance of buffers to deal with psychological stress and also the use of behaviour modification techniques.

Figure 3.1: Models of coping versus non-coping

Coping model	**Non-coping model**
Stressors (behaviour problem in autistic child)	Stressors (behaviour problem in autistic child)
↓	↓
Buffers (social network, hardiness, internal locus of control)	Inability to use buffers (lack of friends, inability to make social links)
↓	↓
Coping behaviour (assertiveness, socializing, good behaviour management)	Non-coping behaviour (depression in mother, aggression to child with autism)
↓	↓
Reinforcement (improved child behaviour)	Deterioration in child's behaviour
↓	↓
Stress reduction.	Increased stress.

Adapted from Groden *et al.* (1994) by M. Fitzgerald.

3.10 Social Support

Cobb (1976) described social support as information leading the person to believe that he is cared for and loved, esteemed and valued, and part of a network of mutual communication and obligation. Byrne and Cunningham (1985) point out that the following are dimensions of social support:

(1) Instrumental assistance.

(2) Information provision.

(3) Emotional empathy and understanding which can be provided on a number of ecological levels, including intimate relationships, extended family networks, friendships and less formal neighbourhood or community contacts.

Caplan and Killilea (1976) define social support as "attachments among individuals or between individuals and groups that serve to promote competence in dealing with short-term crises and life transition, as well as long-term stresses".

Kaplan *et al.* (1977) define social support as the degree to which one's social needs are satisfied through interactions with others. As McGee (1987) points out much confusion has been generated in what is a rapidly developing area by imprecise use of words. She gives an example as the work of Holahan and Moos (1981) in which the authors speak of social support when they are actually assessing social integration. Social support deals with a functional dimension of interpersonal resources. Brown and Harris (1978) found that the perception of access to just one intimate and confiding relationship protected high - risk women from depression. Jenkins, Mann and Belsky (1981) showed that when patients had psychological problems the level of perceived support within the marriage was a major predictor of those who recovered in a G.P. setting within a year.

As McGee (1987) points out many definitions of social support have been forwarded indicating the variety of ways in which this support manifests itself. Schaefer *et al.* (1981) pointed out that social support was initially associated with emotional support.

Functional social support can be divided into two aspects; perceived level of support and perceived adequacy of support. Some researchers have assessed the level or amount of support (e.g. Funch and Marshall, 1984; Holahan and Moos, 1981) while others focus on the appraisal of the adequacy of support (e.g. House, 1981). Except for Barrera (1981) and Henderson *et al.* (1981) few researchers assess both level and adequacy of support jointly yet separately in the same research. There is often an assumption that in measuring high levels of perceived support one is measuring satisfaction. In measuring adequacy or satisfaction, the assumption is that one is provided with a direct indicator of the level of support. This may not indeed be the case and as McGee (1987) points out there is evidence indicating that high levels of support is not necessarily linked with satisfaction. Indeed these high levels of support were more a barometer of the extra stresses experienced by people.

As far as gender and social support is concerned it is clear that women avail of social support more than men (McGee, 1987). She has pointed out that women were twice as likely as men to speak to their social network members about their problems. Studies of coping have shown that the use of interpersonal resources in coping is almost an exclusively female phenomenon both in the general context and in the context of depression (McGee, 1987). She also points out that it appears that women are coached from an early age to be the providers of social support in society. It also appears that more individuals of both sexes are willing to seek help from women than men (Depaulo, 1982). Defares *et al.* (1985) has shown that women are more vulnerable to the effects of detrimental life events than men. Men appear to use to a far greater extent a cognitive

active coping, suggesting an assertive outgoing attitude. Defares *et al.* (1985) point out that women resort to a far greater extent to social support in seeking solutions for their problems.

Alloway and Bebbington (1987) are critical of the buffer theory of social support and conclude that the evidence for buffering role of social support is inconsistent. At the same time Cohen and Wills (1985) concluded that there was a positive association between social support and well-being attributable to an overall beneficial affect of support and to a process of support protecting persons from potentially adverse affects of stressful events. It is also possible that a person may fail to get social support because of a negative network orientation because a man or a women is unwilling to disclose their problems to others and low levels of trust of people (Vaux *et al.*, 1986). Social support has been found to be associated with a number of characteristics of the recipient, such as affiliation and autonomy needs, social competence, self esteem, sociability and locus of control (Cohen, Mermelstein *et al.*, 1985; Cohen and Syme, 1985; Gottlieb, 1985; Lefcourt *et al.*, 1984; Sarason *et al.*, 1983; Sarason *et al.*, 1985). Other studies have shown that situations that threaten self esteem are associated with less received social support (Dunkel-Schetter *et al.*, 1987) and with less support seeking (Folkman *et al.*, 1986). As Brewin *et al.* (1989) point out people who feel themselves to be unusual in some way avoid social contact for reasons other than anxiety. According to social comparison theory (Festinger, 1954) people prefer to compare themselves with similar others when evaluating their abilities or opinions, because similar others are more informative. Brewin *et al.* (1989) found that negative self-appraisal may render individuals much more discriminating in their choice of companions, and lead them to reject others whom they would normally tolerate. They felt it was possible that self-stigmatization could occur in the absence of actual societal rejection. They point out that the self-imposed isolation may be a defense against negative reactions by others that may in reality never materialise. They point out that there is a need for further research why some people simply conceal their problems but otherwise continue to interact normally, whereas others withdraw from virtually all social contact.

The literature on families with handicapped children indicates that they can experience social isolation (Gayton, 1975). These parents feel their relationships with their family and friends are adversely effected by the birth of a handicapped child. These families also report that they rely upon extended family members for many different types of support and assistance in coping with the demands of having a handicapped child.

The role of services in providing support to the family is important. Bristol and Schopler (1983) showed that 70% of children in families experiencing high levels of stress were receiving service provision which by and large did not provide parent support services. It is not necessarily true that services will be supportive of parents and Schopler and Loftin (1969) and Turnbull *et al.* (1978) have noted that some services might even be a source of stress for parents. Bristol and Schopler (1983) found that parents consistently rated parent training and their childrens intervention programmes at the TEACCH centre most supportive. Tavormina *et al.* (1977) found that a two week respite provided by a camping programme improved mothers mental health and made them more capable of coping with their children on their return.

In adolescence a husband maybe less supportive than in the past because the child is not improving as quickly as he hoped and he begins to realise that the handicap is permanent.

This makes it difficult for him to be as interested in his child and support his wife. Some times the roles are reversed and it may be the wife who gets 'burnt out' and it is the husband who has developed a deep attachment for the child and is able to support her in her efforts to work with him (Bristol and Schopler, 1983). Sometimes both parents make the child the centre of their activities and subordinate all their needs and wishes for the child. These parents are at risk of 'burn out'. The best situation is where mother and father join together in mutual support of each other and the child. Single parents with handicapped children experience greater stress than parents with spouses (Beckman-Bell, 1980; Holroyd, 1974).

Parents usually turn to the extended family first for support and help in managing their child with autism. By the time the child reaches adolescence the extended family has either accepted or rejected the family of the person with autism. As the adolescent gets older and stronger grandparents are less able to be supportive.

DeMyer and Goldberg (1983) found that social relations with their friends and neighbours were severely effected in 43% of the families with an autistic person and this showed itself mainly in the direction of reduced contact. There was also difficulty in getting babysitters. Friends and neighbours were also less supportive when the person with autism developed sexually as an adolescent. They had fears about the adolescent's sexuality. Kazak and Wilcox (1984) point out that the overall social networks in families with handicapped children are smaller than those of parents with non-handicapped children. Mothers and fathers of handicapped children name fewer persons who are important to them in providing support. They point out that if parents had a spina bifida child then members of their social network were more likely to know and interact with one another than other families. There was a high network density which could foster a sense of closeness and cohesiveness. Nevertheless it could also generate its own stress and indeed previous social network research indicated that more dense networks may lack "weak ties", or less intimate types of relationships which can provide access to other types of resources and provide new input into the family system (Wilcox and Birkel, 1983). The high level of boundary density in families with handicapped children suggests that these families may be fairly enmeshed. Kazak and Wilcox (1984) suggested that mothers of handicapped children may adapt to the considerable stress they experience concerning parenting issues by "over-loading" their family networks with requests for help, since the costs associated with unreciprocated requests for aid are fewer than made of family than of friends. It appeared to Sloper *et al.* (1991) that social support is mediated by factors internal to the parent and family. They point out that studies finding a relationship between social support and stress in general have not studied personality factors in multivariate analyses. Monroe and Steiner (1986) has suggested that social support may be a function of personality. Crnic *et al.* (1983) has suggested that intra-family support has greater influence on stress than other social support. Friedrich *et al.* (1985) has suggested that coping and social support are interactive with the better copers having more social support and that more social support facilitates coping. Kazak and Marvin (1984) make a distinction between the support from kin and that provided by friends for parents with a spina bifida child. These parents had significantly smaller friendship networks than parents of non-handicapped children. Their networks were also more closely-knit. This network density was found to be associated with higher levels of stress for both mothers and fathers. They concluded that while closely-knit, dense networks can foster a sense of cohesiveness and support, they may also generate stress, as there is less access to other resources, to different view points and fewer opportunities to discuss

network related stress (Granovetter, 1973). It is also interesting that Waisbren's (1980) results found that parents who describe a highly supportive social network had more positive feelings towards their child but also listed more symptoms of stress.

Harris (1994) concludes that "there is good reason to believe that families who include a child with autism may experience greater stress than other families, it is nonetheless, also very important to remember that this impact is quite variable, and that some families may report considerable dysfunction, whereas others say that their functioning is not adversely effected, or in some cases that their family, marital, or personal functioning has been enhanced by the challenge of meeting the child's special needs. A compelling demand for professionals serving families who have a child with autism is to understand what differentiates the adaptive from maladaptively functioning families and how we might enable the less well-functioning family to improve its response to this family crisis".

3.11 Services

Persons with autism require a wide variety of services over the life cycle. There is no cure for autism but a great deal can be done to meet the needs of the person with autism and their family. Professionals normally work as part of a multidisciplinary team of psychiatrists, psychologists, social workers, speech therapists etc. Psychiatrists will have diagnostic assessment roles as well as a treatment role and may function as coordinator of the multidisciplinary team. Paediatricians and other medical personnel will deal with any medical conditions, hearing and visual problems, dental care and genetic counselling. Special education provision will normally be necessary as well as later vocational support and training. There will be a crucial need for family support, counselling and behavioural interventions. They will often need respite care for the person with autism as well as other practical help.

The goals of intervention focus on three basic aims (Rutter, 1985) which take account of the basic problems which persons with autism demonstrate:

(1) Fostering social and communicative development.

(2) Enhancing learning and problem solving.

(3) Decreasing behaviours that interfere with learning and access to opportunities for normal experiences.

In instituting principals of classical and operant conditioning workers and parents will now provide clear warnings that a planned activity is going to change. They will sometimes demonstrate this through the use of drawings. Workers are careful not to reward undesirable behaviours for example only paying attention to a child when they institute some undesirable behaviour. As Lord and Rutter (1994) pointed out it is important to teach alternative reinforceable behaviours to a child in order to terminate unsatisfactory behaviours e.g. teaching a child to shake hands upon greeting rather than to smell other peoples wrists. Providing regular vigorous exercise and setting up a schedule, such as allowing an autistic adolescent to engage in "silly talk" for 15 minutes at the end of the day if he or she has earned credits for not hitting, may reduce the need to develop programmes to deal with aggression (Kern *et al.*, 1984). There are also behavioural techniques developed for severe self injury and aggression (Carr, 1977; Gaylord-Ross, 1980).

LaVigna and Donnellan (1986) were concerned about safe guards against abuse of punishment and developed alternatives to the use of punishment. These were:

(1) Differential reinforcement of alternative behaviour which they describe as the reinforcement of behaviours that are incompatible with the undesired response in intensity, duration or topography.

(2) Differential reinforcement of low rates of responding which they describe as the reinforcement of the undesired response only if at least a specified period of time has elapsed since the last response, or only if fewer than a specified number of the undesired responses occurred during a preceding interval of time.

(3) Differential reinforcement of other behaviour which they described as reinforcement after a specified period of no undesired responding.

(4) Stimulus control which they described as establishing the discriminative control of an undesired behaviour, either through differential reinforcement or fading.

(5) Stimulus change which they described as the non-contingent reward and sudden addition of a novel stimulus or an alteration of the incidental stimulus conditions.

(6) Instructional control which they describe as a differential reinforcement of those responses which are in compliance with the verbal instruction presented.

(7) Shaping which they describe as the gradual modification of some property of responses usually but not necessarily topography by the differential reinforcement of successive approximations to some criterion.

(8) Stimulus sedation which they describe as the continued non-contingent presentation or availability of a reinforcer that reduces the reinforcers effectiveness.

(9) Additive procedures which they describe as a combination of two or more procedures in order to reduce or eliminate an undesired behaviour.

(10) Programming which they describe as an instructional sequence designed to help the person reach certain behavioural objectives based on a functional analysis and involving the systematic manipulation of stimulus conditions, consequences, instructional stimuli, and other variables that have functional relationship with the behaviour.

Using behavioural techniques disruptive behaviour would be treated by:

a) Avoidance of precipitants,

b) Provision of coping skills,

c) Differential reinforcement; feedback to child; rewards for positive behaviours and time out. (Rutter, 1985).

Ivar Lovaas (1980, 1987) has an ambitious behavioural project in which he treats young children with autism in their homes, schools and communities. Through the systematic use of behavioural teaching and some mild aversive techniques (Lovaas *et al.*, 1980), this programme is designed to provide children with intensive programming over almost all their waking hours, 365 days a year. This is accomplished through the use of specially trained student therapists who work in the home and provide training to the child's parents and other care takers. Lovaas' (1987) paper reported findings that almost half the children in the experimental group (40 hours of treatment per week for at least two years) "recovered from autism" and achieved successful performance in regular first grade class rooms. He points out that a fundamental premise is that we must approximate the learning opportunities that are available to a normal child. He points out that the normal child learns in all environments and all the time, including evenings, weekends and vacations. A myriad of behaviours is acquired in a large range of situations, taught by many persons, including peers. He points out that autistic children possess unusual nervous systems and do not learn in this manner. His idea is to provide optimum treatment and education and believes that several adults have to be trained to provide instructions to the child for virtually all of his or her waking hours, in the home, school and community. This team initially consists of several novice therapists, one or more experienced therapists, and parents and eventually peers. The early part of the treatment is full time one to one much of which involves the child learning to imitate, non verbally and eventually verbally. He believes that in order for the behavioural treatment to work it has to be delivered by all significant persons who work with the client as treatment gain is proportionate to the amount of treatment.

This treatment has been criticised by Schopler, Short and Mesibov (1989) who have questioned Lovaas' outcome measures, the adequacy of his control group and the representativeness of his sample. Newson (1992) points out that behavioural programmes have been criticized in that they have been effective at producing controlled imitation at a simple level, but less good at creating flexible self-initiated behaviour; and that they have produced exact copies of patterns of speech which can be used for every day needs, but not spontaneous dialogue flow.

Mesibov (1992) describes social skills group training with high functioning autistic adolescents and adults who meet regularly to share experiences and learn new skills. This involves structured learning lessons and social activities. The skills are then practiced in natural social situations. Mesibov (1992) points out that "the social skills group follow a cognitive, social learning model; improving understanding of social expectations through specific teaching techniques such as role playing and behavioural rehearsal, participating in social activities in natural social settings, and understanding social expectations through discussions and group activities". Mesibov (1992) has also used non-handicapped peers which he feels are more responsive than other handicapped youngsters and can be directed more easily to respond in specific ways. These non-handicapped peers are helpful in teaching social behaviours to individuals with autism. He notes that non-handicapped peers can bring an enthusiasm and energy to social skills programmes. Mesibov (1992) points out that autistic persons have difficulties in understanding social rules. They have trouble reading social cues. This social skills technique is designed to make social situations and expectations as clear as possible by group members. Social rules which are not ordinarily detailed are described in detail and persons with autism are helped to learn these rules.

3.12 Speech and Language Therapy

As Rutter (1985) points out nearly all autistic children are delayed in learning to speak and some never acquire speech. When language does develop there is a failure to use language for social communication, so that autistic persons tend not to talk in a reciprocal to and fro fashion. There is often extensive use of stereotyped phrases and echoing of their own as well as other peoples words. He goes on to point out that the aim is not to give persons with autism "words" although he regards these as useful but rather to facilitate social communication. He points out that autistic children and adults tend not to use language for social communication. For speech and language therapy to be useful there must be evidence of some limited language skills before treatment.

Howlin (1980) describes a home based project for the treatment of autistic children. These programmes were individually designed for each child and in addition to language deficits, many other behaviour problems, such as obsessions, rituals, phobias, temper tantrums, and overactivity were also treated. This was conducted in the parents home and the interventions lasted for 18 months. In an evaluation of this home based behaviourally orientated treatment programme (Rutter *et al.*, 1977; Hemsley *et al.*, 1978; Rutter, 1980; Howlin, 1980, 1981) was compared with those of the more traditional outpatient approach. The findings showed that the results of the home based programme were significantly superior on many behavioural measures. The differences were less marked on language measures. Indeed, there were no significant differences between the groups on tests of language skills, although the home based group tended to perform slightly better. However, the home based group showed better social usage of language. There was no evidence that treatment made any differences to I.Q. It was also apparent that there was considerable individual variation in outcome. The most handicapped children made the least progress, in spite of a comparable investment of therapists time and energy in treatment. The outlook was poor for mentally retarded, mute school age children without babble, imaginative play or understanding of language. Howlin (1980) concluded that on the whole that children who improved most were those who already had use of a few words. The children who made least progress were those who had little comprehension of language, little spontaneous use of sounds or gestures and who had little ability to play. She felt that children for whom operant language programmes were most successful were those who had at least some of the cognitive pre-requisites for language learning, and that behavioural methods are responsible for motivating such children to use their inherent linguistic abilities.

Rutter (1985) concluded that treatment makes most difference to the non-specific problems of autistic children. It makes only a slight difference to language competence and no difference at all to general intelligence. He also pointed out it was necessary to avoid the problem of the gains following treatment only being situation-specific. He felt that autistic children needed to be helped to generalize their behaviour to other contexts. Finally he concluded that the claims of the therapy enthusiasts far exceeded what can in fact be accomplished.

3.13 Medical Needs of Persons with Autism

The medical care of persons with autism is complicated because of some disagreements in the literature about the importance and extent of the necessary medical investigations

(Bailey, 1994). They range from 10% (Rutter *et al.*, 1994) to 12% (Ritvo *et al.*, 1990) to 37% "in an autism group with known medical conditions" (Steffenburg, 1991). Gillberg (1995c) recently pointed out that the average in literature was about 24%. There are also difficulties in obtaining medical information and performing physical examinations. There are also variations in the frequency of assocative medical syndromes and autism. Gillberg (1992a) points out that "the Gothenburg studies have demonstrated that some kind of neurological - neurophysiological impairment is the rule rather than the exception in autism". Some of the main findings from these studies were recently reviewed in Steffenburg (1990). Gillberg (1992a) has suggested that the high rate of associated medical conditions in the Gothenburg material can be attributed "to the comprehensiveness of the work up rather than any particular bias in the material as such". Gillberg's (1992a) full neurobiological work up includes CAT-Scan, EEG, chromosomal culture, auditory brain stem examination, ophthalmological, audiological and otological examinations as well as CSF-analysis. Bailey (1994) suggests that in the absence of clinical indicators of a medical syndrome the following investigations would be recommended:

(1) Chromosome karyotyping, with a cytogenetic or molecular genetic search for the fragile X anomaly and an EEG if seizures are suspected.

The incidence of seizures in persons with autism rises to 25 - 40% by adulthood (Rutter, 1970; Deykin and MacMahon, 1979; Olsson *et al.*, 1988; Volkmar and Nelson, 1990). The most common seizures are motor although complex partial seizures may be more common than realised in the past. There is an association between epilepsy in autism and mental handicap (Bartak and Rutter, 1976; Olsson *et al.*, 1988). The onset of seizures in adolescence is sometimes but not unusually associated with marked behavioural changes and regressions (Rutter, 1970; Kobayashi *et al.*, 1992). There is one peak for epilepsy in early childhood and a second unusual peak during adolescence. Epilepsy was one of the first pieces of information which lead people to think that autism was organic and not psychogenic (Ornitz, 1978). Infantile spasms have a higher risk than normal children of developing autism (Gillberg and Coleman, 1992).

Clearly the management of seizures having been reported were about one quarter of cases studied (Deykin and MacMahon, 1979; Rutter, 1970) will be an important part of the medical management. It may be difficult to diagnose psychomotor seizures in the autistic adolescent because of his already disturbed behaviours. A seizure disorder would be suggested by suddenness of onset, associated facial or other involuntary motor movements, or alterations in level of consciousness after the suspected seizure. At the present stage, with regard to aetiology, one can discern at least four broad groups in autism (Gillberg, 1992a):

(1) Familial autism.

(2) Autism associated with specific medical condition.

(3) Autism with unspecific signs of brain dysfunction without family history of diagnosed medical condition.

(4) Autism without any clear evidence of autism family history or brain dysfunction.

Associated medical conditions in autism include fragile X at 7% (Gillberg, 1992a), 2.7% (Piven *et al.*, 1991), and 1.6% (Bailey *et al.*, 1993). Other associated medical conditions include neurofibromatosis (Gillberg and Forsell, 1984). Hypomelanosis of Ito (Akefeldt and Gillberg, 1991) hypothyroidism (Gillberg, Gillberg, Kopp, 1992), herpes simplex encephalitis (Gillberg, 1986). Although the very few individuals with autism suffer from tuberous sclerosis, recent studies indicate that 21 - 39% of cases of tuberous sclerosis receive a diagnosis of autism (Le Couteur, 1993). The association seem to be confined to those individuals where the tuberous sclerosis is accompanied by mental retardation and epilepsy. Goode *et al.* (1994) in a follow up study found the death rate was more than twice as high in those with an I.Q. below 50 as in those with mild mental retardation or normal intelligence. Rutter (1995) points out that "the death rate was roughly comparable with that in a non-autistic mental disorder group of comparable I.Q.". He also points out that "these deaths occurred in early adult life, usually without accompanying intercurrent disease, open the way to potentially informative neuropathological studies (Bailey *et al.*, 1993).

Genetic counselling will not uncommonly be necessary because the heritability of autism is very high (Folstein and Rutter, 1977; Steffenburg *et al.*, 1989) the rate of autism in siblings shows an increase in risk of some 50 - 100 times. As Rutter *et al.* (1994) point out autism has been shown to be the most strongly genetic of all psychiatric disorders apart from Huntington's disease.

3.14 Social and Community Service Programmes for Persons with Autism

The TEACCH Programme. This programme for the Treatment and Education of Autistic and Communications Handicapped Children (Mesibov *et al.*, 1983). This programme involves parents in a psychoeducational model using both developmental and behavioural theory for its implementation. It is underpined by five guiding principals:

(1) The concept of development.

(2) Individualised diagnostic assessment.

(3) Parents as allies for professionals developing appropriate services.

(4) Structured classrooms.

(5) Specialized procedures and services designed to meet the needs of persons with autism.

Having made the diagnosis the programme focuses on the Psychoeducational profile (Schopler and Reichler, 1979) with younger children. It focuses on imitation, perception, gross motor, fine motor, eye hand integration, cognitive performance, expressive language, self-help skills, social skills, and behaviour problems. This assessment has been expanded to cover the older population of people with autism. In the older age group it focuses on:

(1) Vocational behaviours.

(2) Work related socialization.

(3) Vocational skills.

(4) Self help skills.

(5) Independent work skills.

(6) Leisure activities.

The programme has a focus on parent/professional collaboration where the parent is first a trainee and then the parent is a trainer. There is also a focus on parent-staff emotional support and the difficulties from either side are acknowledged. The parent is also seen as an important social advocate.

3.15 The Jay Nolan Centre Community-based Programme (La Vigna, 1983)

This programme has been influenced by the principal of normalization (Wolfensberger, 1972). The goal of this centre is the development of a full continuum of residential, vocational, recreational, and educational services and programmes for autistic children, adolescents and adults regardless of their level of need.

For each individual in the programme the home staff develops an Individualised Programme Plan based on the results of all assessments, behavioural observations, and individual requests.

There is therefore a continuum of both residential and non-residential services including small group homes, occupational training, Saturday recreation, intensive intervention, in-home respite. Non-aversive procedures are used exclusively to modify behaviour problems.

3.16 Benhaven

This programme (Lettick, 1983) is based on a day and residential school community. Its goal is to achieve optimum development in each person with autism through maximizing the potential for independence and competence in vocational, residential, recreational skills. It provides a flexible individualized programme of services running from childhood into adulthood. It has a school programme and a vocational training programme. In pre-vocational training simple tasks associated with the vocational activities to follow later are presented (Freschi, 1974).

It successfully engaged the students in farm work, (like the programme developed by the Irish Society for Autism at Dunfirth, Co. Meath, Ireland under the direction of Mr. Pat Matthews - 1994 Personal Communication) horticulture and poultry raising were successful. Patients with autism were also successful in button making, mailing and furniture refinishing.

3.17 Homogeneous Placement (persons with autism only) versus Heterogeneous Placement (Mixed versus Specialised Centres)

This section focuses on persons with autism in groups with non-handicapped peers, peers with language and other developmental delays. It is of interest that Rutter (1985) has argued that it is not helpful to adopt a rigid response to diagnostic labels which assumes that because a child is diagnosed as autistic, the only suitable educational placement is in a unit for autistic children. He argued that we need to consider the level and pattern of handicaps when deciding educational placement; some children may do well in a unit for language impaired or mentally handicapped children or, with appropriate support, in a normal school. This flexible approach is especially appropriate as we come to recognise the broader spectrum of autistic problems, and increasingly encounter children with social and language impairments of disproportionate severity. Rutter (1985) went on to state that units that are exclusively for autistic children have the advantage of a concentration of skills involved in children with autism but they have the disadvantage of a lack of peer interactions. He pointed out that units that cater for children with more varied handicaps have the potential for better use of the peer group, but considerable efforts are required for the potential to be realised. He felt that a few of the more intellectually able, and more mildly handicapped, may be suitably placed in an ordinary school if means can be found to adapt to the school situation to cater for any special individual needs of the autistic child. It would appear that some persons with autism could be catered for in a variety of settings if the staff have a detailed knowledge of autism and its core features as well as having the strategies necessary to develop the individualised programmes that these persons with autism need. It would appear unsatisfactory for a person with autism to be placed in a setting where the staff had no knowledge of autism.

Mesaros and Donnellan (1987) point out that the arguments in favour of homogeneous placement are that:

(1) It is easier to operate single classes at one location or even at different locations than to have to disperse services to individual autistic students.

(2) It only requires one group of trained experienced teachers.

(3) Ancillary services can be centralised.

(4) Staff can become familiar with the students needs and can assess students in an on going manner when the students are centralised, as oppose to having students change classes during the day or transfer classes and/or programmes each term. It also prevents students being isolated by non-handicapped peers and from being bullied.

The arguments in favour of heterogeneous placements are:

(1) Modelling and observational learning can occur (Coleman and Stedman, 1974).

(2) Social interactions are promoted and facilitated (Mesaros, 1984).

(3) Communication and play skills can develop for the autistic children (McHale, 1983).

(4) Positive peer attitudes can accrue (McHale and Simeonson, 1980).

(5) Synergistic effects (Olley, 1981) can be minimized when students with behaviour problems are placed with other students who do not exhibit the same problems.

(6) The model can enhance the ability to function in adult, multifaceted, desegregated environments (Donnellan, 1980).

(7) The "Natural proportion" of autistic students to non-handicapped or less handicapped students (Brown *et al.*, 1983) can be realised.

(8) Real friendships can develop.

(9) Students can be exposed to a setting and curriculum that is more congruent with normalization (Wolfensberger, 1972).

Donnellan *et al.* (1987) points out that if educators ultimately want autistic persons to be able to function appropriately in adult, heterogeneous, and complex environments, then autistic students should be matched to and taught in those environments were they can learn what is necessary to live effectively with non-autistic individuals. Students should be placed initially and individually into programmes that are provided with the necessary training and services to support heterogeneous individualised placement. Placement decisions should be based on individual needs rather than on the label "autism".

Section II

Chapter Four

Methods

4.1 Introduction

The first step was to identify all centres in the Eastern Region Health Authority (formally the Eastern Health Board) area with children and adults with special needs up to 25 years of age who were in attendance at these centres. In these centres the persons with special needs had intellectual disability (mental handicap), autism, language problems and/or various other developmental disabilities. Each centre was sent a letter briefly outlining the scope of the study. The letter stated that this study was a prevalence study of autism in the Eastern Region Health Authority area. The staff were asked to identify any person with an "autistic tendency" in the centre. In the Eastern Region Health Authority area the phrase "autistic tendency" was used by staff of centres generally to identify autistic spectrum disorders. The letter was no more than a letter of introduction. It was followed by detailed discussion with the staff of all centres by one of the author's (M.F.) on all features of the Autistic Disorders Diagnostic Checklist. (See Appendix A). Persons with autism had to be born between 1965 and 1989.

(1) The interviews themselves were conducted by two experienced psychologists and provided an opportunity for further sensitization of the staff to autism and to the types of patients the study was attempting to identify during interviewing in 1990/1992. The meeting with the staff member (most knowledgeable about the potentially autistic person) and who knew the person best and was considered as possibly having autism focussed on:

   1) The Autistic Disorders Diagnostic Checklist (Wing, 1987 - Personal Communication) (Appendix A).

   2) A Services Questionnaire (Appendix B).

4.2 Rationale for choosing the Eastern Region Health Authority for this study

The Eastern Region Health Authority was chosen for this study because the author (M.F.) worked in it for 15 years and was very familiar with all the services, and had access to the personnel in all these services. The E.R.H.A. also had a well developed public health service which provided health care in a population - comprehensive way.

The total population of the E.R.H.A. (Census of Ireland 1991) was 1,244,476 or 35% of the national figure. Persons with potential autism will usually be referred by their general practitioner, paediatrician, area medical officer (community care), teacher or indeed parents themselves may present their child to consultant psychiatrists specializing in either child psychiatry or learning disability (mental handicap) for diagnosis. Except in private practise (which plays a very small role in the case of autism) these psychiatrists

work in multidisciplinary teams with psychologists, speech and language therapists, social workers among others. A child psychiatrist conducting private practice would also work in the public health service and therefore no child or person with autism would be missed because they were examined in a private practice setting. All child psychiatrists who worked in either public or private sector co-operated. Ultimately all persons with autism are referred to the public health service. The psychiatrist is usually the team leader. These teams work in close association with residential units who have persons with autism in residence and special schools who have persons with autism in residence or who are day attenders. The multidisciplinary team provides psychiatric, psychological and speech and language assessment. If a formal medical work up is necessary this is usually provided by paediatricians attached to the local paediatric hospital. Indeed many of these referrals for diagnosis will already have seen a paediatrician. Currently the ICD 10 (WHO, 1993) is the most commonly used classification of mental and behavioural disorders in the E.R.H.A. region. All the psychiatrists in either child psychiatry or learning disability (mental handicap) are knowledgeable about autism and the majority will have trained together.

There are centres for persons with autism throughout the E.R.H.A. region (all state funded). A number of those are administered by the E.R.H.A. itself. Other services for persons with autism are provided by the Mater Hospital Child & Adolescent Psychiatric service and associated clinics as well as at St. Paul's Beaumont. There are also extensive services provided by St. John of God network of services, Stewart's Hospital and St. Michael's House (E.R.H.A. Inter Programme Working Group (1994), and Department of Health Report on Services for Persons with Autism (1994)). All these were part of this E.R.H.A. study and fully co-operated.

(2) The second phase of the study focussed on the 100 mothers of autistic persons who lived in the West Dublin and Kildare area of the Eastern Region Health Authority. These mothers were visited in their own homes and the following instruments were administered:

1) The Vineland Maladaptive Behaviour Scale Part I and II (Sparrow *et al.*, 1984).

2) The Index of Social Competence (McConkey and Walsh, 1982).

3) The Family Burden Schedule (Pai and Kapur, 1981).

4) The Social Questionnaire (Corney and Clare, 1985).

5) The General Health Questionnaire (Goldberg, 1978).

Parents were also administered a qualitative questionnaire (see Appendix C).

(3) 51 out of the 100 home based interviews identified children with autism between 5 and 16 years of age. A random sample of 30 was selected from this using Random Number Tables. This sample of 30 was then matched for age, sex and social class with children from the normal school population. The three school role books (Registers) were examined. One of the author's (M.F.) went down the

register from top to bottom with the Principal of the School until a child's name came up which matched for age, sex and social class the child with autism. It was explained to the parents of the control children that a comparison was being made with families with children with autism. All interviews with mothers of the control children were conducted in their homes.

Instruments

4.3 Autistic Disorders - Diagnostic Checklist (A.D.D.C., see Appendix A)

This checklist was developed by Dr. Lorna Wing to provide a basis for a revision of the diagnostic criteria for autism used in the DSM-III (APA DSM, 1980). (Wing L. Personal Communication, 1995).

The goal of the checklist was to identify the expression of autistic behaviours in patients from earliest infancy to young adulthood. The checklist defines three areas of impairment: Section A, impairment in reciprocal social interaction; Section B, impairment in communication, language, and symbolic development; and Section C, restricted repertoire of repetitive behaviours. These three areas (A, B, C) are currently considered by most people working in the field to represent a cardinal constellation of dysfunctions in autism. Using this checklist positively diagnosed children would also meet Rutter's (1978) criteria for autism with the exception of the requirement that diagnosis be made before the child is 30 months of age. Lorna Wing (1987 - Personal Communication) states that this checklist should be used by discussing the child's current behaviours with the professional (teacher, child study team member, paediatrician or other) who knows the child best. Lorna Wing (1987) points out that the A.D.D.C. like the Vineland (Sparrow *et al.*, 1984) "asks for a general description of the child's social behaviour, and then within that framework, the investigators check the appropriate specific items which apply. Do the same for B and C Sections i.e. ask about communication, and then find which behaviours apply, and ask about repeated activities, and find out which, if any are engaged in by the person under assessment". She points out "that if a child shows three behaviours under A, three under B and at least one under C then he or she fits the criteria to be diagnosed as autistic". Lorna Wing (1995 - Personal Communication) states that the Autistic Disorders Diagnostic Checklist will be published by the Journal of Developmental Medicine and Child Neurology in 1996.

4.4 The Services Questionnaire (Appendix B)

This questionnaire was completed by the staff member who knew the person with autism best in the service which this person with autism was attending. The following information was requested: (i) Individual Educational Plans, (ii) staff:client ratios, (iii) other diagnostic categories of patients who shared educational programmes with the person with autism, (iv) type of educational programmes, (v) the other professionals involved with the person with autism as well as the frequency of contact with these various professionals including speech therapists, psychologists etc., (vi) staff were also asked about the parents knowledge of autism and the needs of persons with autism, (vii) finally staff were asked for information on respite care as well as types of training the staff of the unit had undergone in the area of autism. (See Appendix B).

4.5 The Vineland Maladaptive Behaviour Scale Part I and II

Maladaptive levels indicate whether an individual exhibits a significant or non-significant number of maladaptive behaviours when compared with individuals in the same age group of the standardization sample. The Maladaptive Behaviour Scale may be administered only for individuals aged 5 or older. The Maladaptive Behaviour Scale is composed of two parts. Part one describes 27 minor maladaptive behaviours such as temper tantrums, thumb-sucking and impulsiveness and part two describes a further 9 more serious maladaptive behaviours. An example of the items on part one is "is too impulsive" and an item from part two "displays behaviours that are self-injurious", stereotypic and destructive behaviour.

The interviewer introduces the domain with a statement such as "from time to time, individuals exhibit behaviours that are considered undesirable". The interviewer describes that behaviour in each item of the Maladaptive Behaviour Scale, and asks the parent or caregiver to say whether the individual usually, sometimes, or never engages in the activity.

The item scores 2, 1, and 0 are applied to the Maladaptive Behaviour Scale. A high score on maladaptive behaviour items reflects more negative behaviours. The interviewer scores 2 if the individual usually or habitually engages in the activity described by the item. The interviewer scores 1 if the individual sometimes engages in the activity described by the item. The interviewer gives the individual a score of 0 if he/she never or very seldom engages in the activity described by the item.

The split-half reliability coefficients for the Maladaptive Behaviour Scale range from .77 to .88 (median = 0.86). The split-half reliability coefficients for the Maladaptive Behaviour parts one and two are .85 or higher. As far as internal consistency is concerned for the Maladaptive Behaviour part one the median split-half reliability coefficient is 0.86. The test - retest reliability coefficients for the Maladaptive Behaviour Scale part one are .88 indicating good test retest reliability. Construct validity of maladaptive behaviour scale is shown by the fact that the Maladaptive Behaviour Scale does not possess the developmental characteristics of the adaptive behaviour scale.

4.6 Index of Social Competence

The Index of Social Competence (McConkey and Walsh, 1982) covering 15 areas of ability, has been developed and evaluated for use in surveys of persons with mental handicap to study what their needs for services are and used as a screening assessment of individual clients prior to more detailed programme planning. It consists of:

(1) Additional handicaps:

a) Visual,

b) Hearing,

c) Epilepsy.

(2) Communication skills:

a) Instructions,

b) Communication.

(3) Self-care skills:

a) Eating,

b) Personal needs,

c) Mobility,

d) Hands,

e) Around the house (helping),

f) Preparing food.

(4) Community skills:

a) Reading,

b) Writing,

c) Time,

d) Money.

It was developed to be completed during an interview with a person who knew best the person e.g. a parent or a staff member with whom the person had most contact or who knew him or her longest who is asked to describe the person's best level of functioning. On the Index of Social Competence high scores indicate increasing dependency on others. The Index of Social Competence had Pearson Product Moment Correlations calculated among the ratings of the subscales. There was a significant degree of inter-correlation among the subscales; the three exceptions being Vision, Hearing and Epilepsy. However, the size of these correlations was generally around 0.5 (range 0.182 - 0.800) indicating that a sizeable degree of variance remained unique to each subscale. The inter-correlated subscales were then factor analysed using an orthologonal varimax rotation with ultimately a three factor solution. The three main factors underlying social competence were as follows:

Factor One: Community Skills - this included the ability to handle money, tell the time and simple literacy skills; all of which are essential to independent living within the community.

Factor Two: Self-Care Skills - by contrast, this factor is concerned with the skills needed to look after ones self - self feeding and preparing food, washing and dressing, and tidying the home. To succeed in these tasks, clients also need to be mobile and to have use of their hands.

Factor Three: Communication Skills - the two subscales loading highest on this factor are those dealing with the ability to communicate with others and the understanding of other people's communication.

From this analysis it was possible to complete a profile of abilities for each client. The high ability group had scores above the median on all three factors (29%). The low ability group had scores below the median on all three factors (20%). The remainder of the sample had a "mixed ability profile" (51%) (McConkey & Walsh, 1982).

Validity was ascertained by examining whether a predictable relationship with an independent variable is in fact obtained. Evidence for the validation of the Index of Social Competence came from the fact that families with a highly dependent son or daughter expressed a more immediate need for residential care facilities than those with more able offspring. It was found that the majority of the low ability group (53.9%) anticipated the need for residential care while only 15.6% of the high ability group did so in a study of 376 mentally handicapped patients. A check was made on the inter-rater reliability of the Index of Social Competence by comparing the ratings made by parents and those of staff who knew the mentally handicapped persons well. The staff agreement with parents ratings were reasonably high - 75% communication scale; 78% self care scale and 72% community skills scale (McConkey and Walsh, 1982). The Index of Social Competence systematizes information about an individual's current level of functioning in everyday life and is quickly administered and readily understood by respondents.

McEvoy & Dagnan (1993) showed that the instrument was highly internally consistent and discriminated between people living in hospital, in staffed community homes and in the homes of their families.

4.7 Family Burden Schedule (Pai and Kapur 1981)

The Family Burden Schedule is a semi-structured interview schedule to assess the burden placed on families with psychiatric patients. The interview focuses on various areas of burden the families might have experienced due to the psychiatric patients. The respondents during the interview were encouraged to be objective and concrete in their responses. For instance, if they said they had experienced financial burdens they were asked to give details of expenses on travel etc., of loss of pay and so on. If they said their leisure was curtailed they were asked how they had spent it previously and in what manner and to what extent a particular leisure activity was now curtailed. For each item (N = 24) level of burden were recorded as absent (scored zero), moderate (scored 1), and severe (scored 2). In addition there was a final domain which focussed on subjective burden on the family (N=1 question). There was also a scoring system with no burden being scored 0, moderate burden being scored 1, and severe burden being scored 2. The interview schedule has 6 major domains:

(1) Financial burden.

(2) Disruption of routine family activities.

(3) Disruption of family leisure.

(4) Disruption of family interaction.

(5) Effect on the physical health of others.

(6) Effect on mental health of others.

An inter-rater reliability study showed that for the category of financial burden the inter-rater reliability coefficients (df = 2 throughout) ranged from 0.94 to 0.99. For the category of burden focussing on effect on the family routine inter-rater reliability coefficients ranged from 0.88 to 0.97. For the category of burden focussing on the effect on family leisure inter-rater reliability coefficients ranged from 0.87 to 0.93. For the category of burden focussing on the effect on family interaction inter-rater reliability coefficients ranged from 0.94 to 0.99. For the category of burden focussing on the effect of physical health of other family members inter-rater coefficients ranged from 0.90 to 0.98. For the category of burden focussing on the effect on mental health of other family members inter-rater reliability coefficients ranged from 0.87 to 0.94. The reliability of the interview schedule was examined by the following method. A relative of a patient was interviewed by three raters, one of them putting the questions to the relative. Each rater scored every item individually without consulting the others. The ratings were then compared and the differences were examined for statistical significance by determining a reliability coefficient, the method being based on a two-way analysis of variance. The reliability score was above 90 per cent for 20 items and between 81 per cent and 89 per cent for the other four. Relatives found that the highest burdens were financial loss, disruption of normal family activities and the production of stress symptoms in family members, in that order.

In order to test the validity of the instrument, the subjective burden as reported by each relative was scored on a 3 point scale:- absent (scored 0), moderate (scored 1), or severe (scored 2). It was considered that if the overall objective burden assessed by the raters was highly correlated with the subjective burden as reported by the relative, it would be an indirect though not an absolute, method of measuring the validity of the instrument. In fact, the correlation coefficient between the mean total scores on each item as assessed by the professional raters and by the relatives was 0.72 (df = 1). The authors, Pai & Kapur, (1981) considered this sufficiently high.

4.8 The Social Problem Questionnaire (Corney and Clare, 1985)

The Social Problem Questionnaire is a short, 33 item self-report questionnaire identifying social problems, difficulties and dissatisfactions. The questionnaire covers housing, occupation, finance, social and leisure activities, child-parent and marital relationships, relationships with relatives, friends, neighbours and work mates, and legal problems. It is a useful measure of the presence/absence of social problems in general in all groups of populations. The social questionnaire (see Appendix F) is scored by giving somebody who makes a tick in any question of a domain indicating marked or severe problem is counted as a person having a "marked problem" in this area. A tick indicating minor is counted as a "minor problem". The individual items are rated on a four point scale which ranges from '0', indicating no problems, to '3' indicating severe social difficulties. The subject are classified as having a major problem in a particular domain when he/she indicates marked or severe difficulties or dissatisfactions on one or more items within the

category concerned. However, with the marital rating, many respondents would not admit to a marital problem unless they were on the verge of separating. The scoring is therefore different on questions relating to marriage (18 - 22); a response of "no difficulty" is scored 0, "slight difficulty" is scored 1, "marked difficulty: is scored 2, "severe difficulty" is scored 3. If a person has a score of 4 or more on these five questions he or she is rated as having marked marital problems. The social questionnaire can also be used to divide populations into those with no social problems and those with one or more (Corney R. 1989 Personal Communication). The latter group are those who have indicated a marked or severe problem in any of the questions. The Social Questionnaire has been adapted from the existing Social Maladjustment Schedule (Clare and Cairns, 1978) whose value has been demonstrated in several studies of patients in general practice (Cooper *et al.*, 1975; Corney, 1981) and of patients with mixtures of physical and psychological symptomatology (Clare, 1980) and in studies of the effect of social problems on clinical outcome (Cooper *et al.*, 1975; Huxley and Goldberg, 1975).

Estimates of validity were performed by comparing responses to the questionnaire with those obtained using the Social Maladjustment Schedule (Clare and Cairns, 1978). Validity was also measured by comparing scores on the Social Questionnaire among different samples of the population. For social work referrals, the social workers assessments were compared with the clients responses on the questionnaire. Two coefficients of agreement IA (a) and IA (p) were calculated for each of the domains already mentioned. These were based on the ratings of absence or presence of the major problem or maladjustment using the scoring system described earlier. IA (a) is the proportion of time the raters agreed when at least one of them gave a rating of 'no' or 'minor' problems, IA (p) is the proportion of times the raters agreed when at least one of them rates the problems as 'major'.

The following coefficients of agreement between questionnaires and interviews were found for G.P. (General Practice) attenders:

Housing IA (a) 0.79; IA (p) 0.57;
Finance IA (a) 0.83; IA (p) 0.63;
Social activities and relationships IA (a) 0.71; IA (p) 0.50.

The other domains ranged between 0.20 to 0.93.

The overall specificity and sensitivity in general practice attenders were:

Sensitivity 0.81 Specificity 0.92.

The coefficients of agreement between questionnaires completed between subjects and social worker assessment were as follows:

Housing IA (a) 0.84; IA (p) 0.67
Marriage or relationship with opposite sex IA (a) 0.80; IA (p) 0.48.
Sensitivity 1.00 Specificity 0.67.

There was some degree of discrepancy between ratings made using the interview schedule and those made using the Social Questionnaire. These discrepancies normally occurred in any one item between the ratings of minor, major and severe. The majority of

the patients rated as '0' on an item of the Social Questionnaire were also rated as having no problems or satisfied on the Social Maladjustment Schedule. This explains why the figures for IA (a) were higher than those for IA (p).

The specificity ratings for the instrument, were in general, much higher than those measuring sensitivity, suggesting that the instrument tends to yield few false positives in most of the domains. The ratings were much higher in populations with many social problems. When a comparison of the Social Questionnaire was made to those obtained using the Social Maladjustment Schedule in many cases people seemed more ready to admit to certain problems on a questionnaire than being interviewed.

The self report Social Questionnaire was found to be simple to administer and readily acceptable to general practice patients, psychiatric outpatients and social work clients, as well as the general population. It was found to be a useful measure of the presence-absence of social problems in general in all groups of populations.

4.9 General Health Questionnaire (Goldberg, 1972)

The General Health Questionnaire (GHQ) (Goldberg, 1972) is used to identify patients in general practice and community settings who are suffering from non-psychotic psychiatric ill health. The General Health Questionnaire exists in various forms of which the 30 item questionnaire is frequently used. Each item consists of a question asking whether the respondent has recently experienced a particular symptom or item of behaviour on a scale ranging from 'less than usual' to 'much more than usual"

The following is an example of an item:-

Have you recently been finding life a struggle all the time?

Not at all	No more than usual	Rather more than usual	Much more than usual
Score 0	Score 0	Score 1	Score 1

The GHQ is a highly sensitive and specific screening tool for the detection of psychiatric disturbances in community populations. Sex as well as race, age, social class and employment status have no clear effect on screening (Goldberg, 1978). The test - retest reliability coefficient was shown to be 0.90 for patients who were also given a standardized psychiatric interview on each testing occasion. The split-half reliability was shown to be 0.95. The scale has also been shown to be valid. Goldberg, Rickels, Downing and Hesbacher (1974) compared the use of the 30 item GHQ with independent clinical assessment (clinical interview schedule) and found a +0.70 correlation of clinical assessment, a sensitivity of 81.4% and a specificity of 83.9% using a threshold score of 4/5. The subjects scoring on or above the cut off point of 5 in the 30 item form are classed as potential or probable psychiatric cases; those scoring below these cut off points are classed as probably non-cases. The GHQ has been used to study the relationship between psychiatric and physical ill health in general and specialized medical settings (Depaulo *et al.*, 1980; Gardner, 1980; Goldberg, 1970; Krupinski *et al.*, 1971). It has been used in a variety of national and cross national studies (Harding, 1973; Mann, 1977; Munoz *et al.*, 1978).

4.10 The Parents Questionnaire

The Parents Questionnaire was a qualitative questionnaire. It requested information on the type of services available to the autistic person. It requested information on what diagnosis was received by the parents and how old the child was when the diagnosis was made including other information.

4.11 Interrater Agreement of the Autistic Disorders Diagnostic Checklist[1]

One of the author's (M.F.) conducted a series of interviews using the A.D.D.C. (Wing 1987 - Personal Communication) with key workers of persons with special needs. In total 28 interviews were conducted. One of the author's (M.F.) conducted the interviews and videotaped them. Each videotaped interview was then scored by two psychologists who were very knowledgeable about autism. All raters were blind to the diagnosis. Before they commenced coding they had detailed discussions with one of the author's (M.F.) about each item of the Autistic Disorders Diagnostic Checklist. They had no information except the responses to the Autistic Disorder Diagnostic Checklist on videotape.

When the interrater agreement study was complete it emerged on a re-examination of the cases that they had an age range from 5 to 25 years (N=28), with an average age of twelve years (sd=6.25). There were 26 males and 2 females. Fourteen persons received a diagnosis of autism as a primary diagnosis on the A.D.D.C.. Fourteen did not receive a diagnosis of autism. Level of ability of this group was based on scores (from case notes) on either the Stanford-Binet Intelligence Scale (Thorndike *et al.*, 1986), the Wechsler Intelligence Scale for Children -Revised (WISC-R) (Wechsler, 1974) or the Wechsler Adult Intelligence Scale (WAIS-R) (Wechsler, 1981). The IQ of the group ranged from 30 to 90. (It was not possible to calculate the average IQ score because different IQ tests were used). The social class (O'Hare, 1982) of these persons are as follows:

Social Class 1	N=4	Social Class 2	N=3
Social Class 3	N=5	Social Class 4	N=7
Social Class 5	N=4	Social Class 6	N=1
Social Class 7	N=4		

Nominal scaled data permits an analysis only of interrater agreement. The use of Kappa is recommended when the same *two* judges rate each subject. In this study the Kappa coefficient was used to calculate the proportion of agreement between the two raters (G.B. & J.O'C.) after chance agreement has been removed from consideration. A Kappa coefficient can vary from 1.00 to -1.00, a coefficient of 0 indicates that the observed agreement is exactly equal to the agreement that could be expected by chance while a coefficient of 1 indicates perfect agreement between raters. In the next section the Kappa coefficient for all 83 items comprising the A.D.D.C. is presented.

[1]The distinction between interrater reliability and interrater agreement blurs when one deals with nominal scales. Since the rating categories do not differ quantitatively, the disagreements in categorisation generally do not differ in their severity (except when some disagreements may be more serious than others, in this case the weighted kappa is calculated to differentially weight disagreements among nominal ratings). Agreement becomes an absolute; ratings are either in agreement or disagreement. As a result, no distinction exists between interrater reliability and interrater agreement for nominal scales. The term interrater *agreement* is more appropriate, since it is more consistent with the terminology employed at the ordinal and interval levels of measurement (Tinsley & Weiss, 1975).

Table 4.1: Interrater Agreement A.D.D.C.

Section A

1. **Absence or impairment of use of eye to eye gaze, facial expression, body posture and gestures to initiate and modulate reciprocal social interaction**

	Kappa	Agreement
a. Does not anticipate being held	.63	95%
b. Does not adapt posture, cuddle in when held, may stiffen and resist when held	.71	95%
c. Does not look or smile when making a social approach	.91	99%
d. Does not use eye contact to get someone's attention.	.93	99%
e. Does make eye contact, but does so inappropriately	1.0	100%
f. Does make social approaches, but does not use variations in eye to eye gaze	1.0	100%

2. **Absence of impairment of interactive play or sharing of interests**

	Kappa	Agreement
a. Does not reciprocate in lap play	.77	96%
b. Does not point things out to others and use eye contact in order to share the pleasure of seeing something interesting	1.0	100%
c. Does not spontaneously bring toys or other possessions to show other people to share pleasure and interest.	1.0	100%
d. Self chosen play activities are solitary	1.0	100%
e. Involves other children only as mechanical aids	1.0	100%
f. Directs other children as 'puppets' in a repetitive game. No interest in other children's suggestions	.84	99%
g. Amiably accepts passive role in other children's play but makes little or no contribution	1.0	100%
h. Engages with one other specific person who has the same circumscribed interest. The social interaction is dominated by the one theme	1.0	100%

3. **Abnormalities of greeting behaviour**

	Kappa	Agreement
a. Does not rush to greet parent after a period of separation	.81	98%
b. Does not spontaneously wave to greet or when saying goodbye	1.0	100%
c. Ignores visitors to the house, classroom	1.0	100%
d. Says 'hello' or some stereotyped phrase but only when prompted, or because of previous training	.84	98%
e. Makes approaches indiscriminately and inappropriately to familiar people and strangers alike	.86	98%

4. **Abnormalities in seeking comfort**

	Kappa	Agreement
a. Never seeks comfort. Appears to ignore pain, heat, or cold	.92	99%
b. Seeks comfort, but only in a mechanical way	1.0	100%
c. Shows distress if hurt, but does not come for comfort	.92	99%
d. Approaches others if hurt, but in a stereotyped way, and does not seek or respond to comforting	1.0	100%
e. Approaches others, intrudes upon them, may cling tightly to them regardless of the needs and feelings of the person approached	.93	99%

5. **Abnormalities in giving comfort to others**

	Kappa	Agreement
a. Ignores existence of and walks through and over other people, regardless of their feelings. Is unaware of others' 'personal space'	1.0	100%
b. Indifferent to others' pain or distress or may laugh at others' distress	.93	99%
c. Is distressed by injury or illness in another person, but only because of change of appearance or routine. Does not offer comfort or sympathy	.84	99%
d. No intuitive awareness of others' pain or distress, but has some understanding on an intellectual level if problem is explained.	.93	99%

6. **Impairment of imitation**

	Kappa	Agreement
a. No spontaneous imitation of others' actions	1.0	100%
b. Automatic, mechanical imitation of others' actions without real appreciation of the meaning, sometimes amounting to echopraxia equivalent to echolalia in speech	1.0	100%
c. May imitate simple movements, but fails to engage in imitative make-believe play	.92	99%
d. Does imitate actions of one person, animal or object	.84	99%
e. Does try to imitate other people's actions, and is aware of necessity for correct social behaviour, but gets details wrong in a naive, even bizarre fashion.	.90	99%

7. **Impairment of ability to make friendships (mutual sharing of interests and emotions)**

	Kappa	Agreement
a. No peer friendships despite ample opportunities	.93	99%
b. Poor relationships with peers - other children tend to tease and bully	.93	99%
c. Wants friends but has poor grasp of the concept of friendship.	1.0	100%
d. Has one 'friend', but has a limited, passive role in the partnership	*	100%
e. Has a friend with the same circumscribed interest - talk 'at' each other mainly concerning this interest	1.0	100%

* Statistics cannot be computed when the number of non-empty rows or columns is one

8. **Impairment of development of social aspects of pretend play**

	Kappa	Agreement
a. Fails to 'animate' toy animals and dolls or objects	.85	98%
b. Does appear to 'animate' one or a few toys or other objects	1.0	100%
c. Invents a fantasy person or people, even an entire imaginary world	.87	99%

9. **Impairment of awareness of social rules**

	Kappa	Agreement
a. Lack of awareness of need for personal modesty	1.0	100%
b. Lack of awareness of psychological barriers	.93	99%
c. Lack of awareness of social taboos in conversation	.91	99%
d. Lack of awareness of correct behaviour in public	.93	99%

Section B

1. **Impairment of use of language for communication**

	Kappa	Agreement
a. In the pre-verbal stages of development, no meaningful intoned vocalizations, or communicative babbling	.84	98%
b. At stage when speech should be present, has no spoken language and failure to compensate such as gesture and mime	1.0	100%
c. Has speech, but neither initiates nor sustains a conversation with others	1.0	100%
d. Makes approaches to others, but content of speech is one-sided, repetitive, without appropriate conversational turn-taking	.92	99%

2. **Impairment of comprehension of language**

	Kappa	Agreement
a. No response to communication of others	1.0	100%
b. Responds to communication of simple instructions, but only in a familiar context; actions due to learned habits rather than understanding of words	1.0	100%
c. Responds to single words or phrases out of context, rather than the meaning of a whole statement	.79	98%
d. Understands a wide range of words and grammatical constructions, but has marked tendency to interpret information in a literal way, failing to take the context into account, leading to naive mistakes	1.0	100%

3. **Impairment of use of speech (if present)**

	Kappa	Agreement
a. Stereotyped and repetitive use of speech; immediate echolalia and/or repetition of phrases in a mechanical way.	1.0	100%
b. Problems with words that change in meaning with the context. Most obviously shown in reversal of pronouns	.89	99%
c. Idiosyncratic use of words or phrases; these may be incorrect, concrete, literal, inverted, or actual neologisms	.84	99%
d. Grammatical speech and large vocabulary, but use of speech long-winded, pedantic, lacking in colloquialisms, repetitive	.47	98%
4. Abnormalities in pitch, stress, rate, rhythm, volume or intonation of speech	.92	99%

5. **Impairment of symbolic development as shown in imaginative activities**

	Kappa	Agreement
a. No appropriate use of miniature objects, despite language comprehension age of 2 years or above	.92	99%
b. Shows appropriate use of miniature objects when presented in test situation	1.0	100%
c. Uses some toys spontaneously in an appropriate way, but play is repetitive and does not include the use of one object to represent another of a quite different kind	1.0	100%
d. Has representational play, which may be elaborate but this is limited to the one theme and is markedly repetitive	.63	98%

Section C.

1. **Stereotyped repetitive postures or bodily movements**

	Kappa	Agreement
a. Tends to stay in one position with little or no spontaneous activity	.87	99%
b. Moves around aimlessly	.85	98%
c. Simple repetitive bodily movements	1.0	100%
d. More complex repetitive movements	1.0	100%

2. **Stereotyped repetitive activities related to bodily functions or sensations**

	Kappa	Agreement
a. Smearing or other manipulation of saliva or excreta	1.0	100%
b. Searches for and swallows inedible objects	1.0	100%
c. Repetitive self injury	.84	98%
d. Preoccupation with visual, auditory, olfactory or tactile sensations	.92	99%

3. **Preoccupation with objects, regardless of their function**

	Kappa	Agreement
a. Unusual attachment to objects	1.0	100%
b. 'Collects' certain kinds of objects for no apparent purpose	.89	99%
c. Arranges objects in straight lines or patterns, upset if arrangements are disturbed	.76	98%
d. Preoccupation with parts of objects, animals or people	.84	99%
e. Preoccupied with repetitive actions, involving objects	.92	99%
f. Preoccupation with specific abstract attributes of objects or people, such as colour, shape, sound, number	*	98%

4. Preoccupied with maintenance of small details of the familiar environment	.53	96%
5. Preoccupied with the maintenance of certain familiar routines	.70	96%

6. **Restricted and repetitive patterns of interests of a verbal or intellectual kind**	Kappa	Agreement
a. Asks the same questions repeatedly, regardless of the replies received	.75	98%
b. Acts the role of an object, animal, fictional character or real person in a repetitive stereotyped way regardless of suggestions from other children	.65	99%
c. Preoccupied with special interests dependent on good rote memory, ability to calculate, or musical ability	1.0	100%
d. Preoccupied with particular subjects; tends to amass facts but usually lacks depth of understanding	.65	99%
7. Life style is restricted, empty, routine bound.	.93	99%

* Statistics cannot be computed when the number of non-empty rows or columns is one

The data collected on the A.D.D.C. will also be used to code from DSM-III-R draft criteria, ICD10 draft research criteria, Kanners 5 points, Kanner and Eisenberg (1956) two criteria, Aspergers Syndrome, Wing and Gould (1979) Triad of social interaction, imagination, and repetitive activities and communication impairments (see Appendix J).

4.12 Interrater Agreement for questionnaires used in the parental interviews

One of the author's (M.F.) interviewed primary caretakers of persons with special needs who were day attenders at ERHA units/schools. Twelve interviews in total were conducted.

These interviews focused on:

(1) The Vineland Maladaptive Behaviour Scale - Part 1 & 2.

(2) Index of Social Competence.

(3) Family Burden Schedule.

The answers to these questions were audiotaped in the primary caretakers home. No other information was audiotaped. These audiotapes were then given to two independent raters (experienced psychologists) who knew nothing about the family of the persons with special needs. Before reliability coding began there were detailed discussions on each item of the instruments between the two coders. Level of agreement between the two raters for the three scales listed above are reported in the next section, findings for the Vineland Maladaptive Behaviour Scale are presented first.

Overall agreement for the scale was calculated by using the agreements plus disagreements for all items as the base and the agreements as the numerator. Agreement levels and Kappa values for individual items are presented in Table 4.2 and Table 4.3. A count of the number of agreements may result in artificial elevated values because, simply by chance, some agreement may occur, therefore interrater agreement was calculated using Kappa (Cohen, 1960) (which takes into account chance agreement).

Table 4.2: Interrater Agreement and the the Vineland Maladaptive Behaviour Scale - Part 1.

	Kappa	Agreement
1. Sucks thumb or fingers	1.00	100%
2. Is overly dependent	1.00	100%
3. Withdraws	1.00	100%
4. Wets bed	1.00	100%
5. Exhibits an eating disturbance	0.87	92%
6. Exhibits a sleep disturbance	1.00	100%
7. Bites fingernails	1.00	100%
8. Avoids school or work	0.86	92%
9. Exhibits extreme anxiety	1.00	100%
10. Exhibits tics	0.80	92%
11. Cries or laughs to easily	0.87	92%
12. Has poor eye contact	1.00	100%
13. Exhibits excessive unhappiness	1.00	100%
14. Grinds teeth during day or night	0.82	92%
15. Is too impulsive	1.00	100%
16. Has poor concentration or attention	1.00	100%
17. Is overly active	1.00	100%
18. Has temper tantrums	1.00	100%
19. Is negativistic or defiant	0.85	92%
20. Teases or bullies	1.00	100%
21. Shows lack of consideration	1.00	100%
22. Lies, cheats or steals	1.00	100%
23. Is too physically aggressive	1.00	100%
24. Swears in inappropriate situations	1.00	100%
25. Runs away	1.00	100%
26. Is stubborn or sullen	1.00	100%
27. Is truant from school or work	-*	100%

* Statistics cannot be computed when the number of non-empty rows or columns is one.

Table 4.3: Interrater Agreement and the Vineland Maladaptive Behaviour Scale - Part 2.

	Kappa	Agreement
28. Engages in inappropriate sexual behaviour	1.00	100%
29. Has excessive or peculiar preoccupation with objects or activities	1.00	100%
30. Expresses thoughts that are not sensible	1.00	100%
31. Exhibits extremely peculiar mannerisms or habits	1.00	100%
32. Displays behaviours that are self-injurious	1.00	100%
33. Intentionally destroys own or another's property	1.00	100%
34. Uses bizarre speech	1.00	100%
35. Is unaware of what is happening in immediate surroundings	1.00	100%
36. Rocks back and forth when sitting or standing	1.00	100%

The was a satisfactory level of agreement between the two raters on the Index of Social Competence also. The overall level of agreement was 98%, the ratings were based on

eight persons with disability since four persons were not old enough to be rated on the Index of Social Competence. Percentage agreement and kappa values for each item are displayed in the following table (Table 4.4).

Table 4.4: Level of agreement and Kappa between two raters for the individual items on the Index of Social Competence

Item	Kappa	Agreement
Vision	-*	100%
Hearing	-*	100%
Epilepsy	-*	100%
Instructions	1.00	100%
Communication	1.00	100%
Eating	1.00	100%
Personal needs	1.00	100%
Mobility	-*	100%
Hands	0.81	87.5%
Around the house	1.00	100%
Preparing food	-^	87.5%
Reading	1.00	100%
Writing	1.00	100%
Time	1.00	100%
Money	1.00	100%

* Statistics cannot be computed when the number of non-empty rows or columns is one.
^ Kappa cannot be computed because row values do not equal column values.

Table 4.4 shows the level of agreement between the two raters. There was little disagreement on such items as vision, hearing, history of epilepsy, mobility, ability to read and write, understanding of time and money.

Level of agreement and kappa values for the 25 individual questions on the Family Burden Schedule are presented in the following table (Table 4.5). The overall level of agreement between the two raters for this scale was 98%.

Table 4.5: Level of agreement and Kappa between two raters for the individual items on the Family Burden Schedule.

Item number on the Family Burden Schedule	Kappa	Agreement
Question 1	1.00	100%
Question 2	1.00	100%
Question 3	1.00	100%
Question 4	1.00	100%
Question 5	1.00	100%
Question 6	1.00	100%
Question 7	1.00	100%
Question 8	1.00	100%
Question 9	1.00	100%
Question 10	0.86	92%
Question 11	1.00	100%
Question 12	1.00	100%
Question 13	1.00	100%
Question 14	0.82	92%
Question 15	-^	92%
Question 16	0.86	92%
Question 17	1.00	100%
Question 18	1.00	100%
Question 19	1.00	100%
Question 20	1.00	100%
Question 21	1.00	100%
Question 22	1.00	100%
Question 23	0.87	92%
Question 24	1.00	100%
Question 25	0.80	92%

^ Kappa cannot be computed because row values do not equal column values.

As can be seen from Table 4.5 there was a satisfactory agreement between the two raters. Findings from the data analyses are presented in the results section. The average age of the persons with special needs was twelve years (sd=6.37) ranging from seven years to 25 years of age. There were eleven males and one female. Level of ability (from case notes) for these twelve persons with special needs in this interrater agreement study was based on scores from the Stanford-Binet (Thorndike *et al.*, 1986), the WISC-R (Wechsler, 1974) or the WAIS-R (Wechsler, 1981) and it ranged from an IQ of 30 to 75. (It was not possible to calculate the average IQ score as different measures were used). Three of the people in this group with special needs were in social class 1 (O'Hare, 1982), another three people were in social class 2, two were in social class 3, there was one each in social class 4 and 5 and the remaining two people were in social class 7. Nine of the twelve cases included in this group received a diagnosis of autism on the A.D.D.C. (Wing 1987 - Personal Communication) and the other three were non-autistic mentally handicapped.

Section III

Chapter Five

Results

The following section presents the findings of this investigation into the prevalence of individuals with autism in the Eastern Region Health Authority (formally the Eastern Health Board) region who were in contact with services.

Staff identified 309 potentially autistic persons throughout the Eastern Region Health Authority region. No centre refused to participate in the study. All 25 centres were providing services to people with autism or intellectual disability or with other special needs. A total of 272 of these met the criteria for autism on the Autistic Disorders Diagnostic Checklist (A.D.D.C., Wing 1987 - Personal Communication).

Demographic information of the 272 persons with autism are presented in the following sections. Scoring for each item of A.D.D.C. is also presented.

Following this there is an account of the psychosocial aspects of having a person with autism in the family. This information was attained from interviews with 100 mothers of persons with autism. Mothers provided information on their son's or daughter's behavioural characteristics and competencies. Findings on family burdens experienced, social problems encountered due to having a person with autism in the family are also presented. An estimate of the mothers general health and well being is also presented.

Finally findings from an interview with key workers working with persons with autism are presented.

5.1 Prevalence of Persons with autism in the Eastern Region Health Authority

An overall prevalence was calculated for the catchment area of the Eastern Region Health Authority by examining the numbers of persons with autism identified in this study in relation to the total number of births spanning the period from the birth of the oldest of the persons with autism to that of the youngest. The information was obtained from the relevant census figures and indicates an approximate overall prevalence of 4.95 per 10,000 of the population using the Autistic Disorders Diagnostic Checklist (Wing, 1987 - Personal Communication). (See Table 5.1).

Table 5.1: Prevalence of autism

Overall Prevalence		
Total Population (0 - 25 years)	549.255	(Based on census figures for E.R.H.A. Area) (Census of Ireland 1991)
Total Numbers with Autistic Disorder	272	(Attending services in the E.R.H.A. Area)
Prevalence = $\frac{272}{549,255}$ X 100 =	0.0495%	or 4.94 per 10,000 pop.

The number of persons with autism attending each centre in the Eastern Region Health Authority region is presented in the following table. As can be seen from Table 5.2 some centres only had one or a few persons with autism.

Table 5.2: The number of persons with autism attending each centre in the Eastern Region Health Authority region.

Centre No.	**No.**	**Centre No.**	**No.**
Centre 1	8	Centre 15	2
Centre 2	1	Centre 16	1
Centre 3	2	Centre 17	6
Centre 4	3	Centre 18	8
Centre 5	3	Centre 19	30
Centre 6	7	Centre 20	10
Centre 7	5	Centre 21	12
Centre 8	0	Centre 22	37
Centre 9	14	Centre 23	18
Centre 10	1	Centre 24	41
Centre 11	11	Centre 25	34
Centre 12	15	Centre 26	5
Centre 13	1		
Centre 14	2		

The age profiles of the persons with autism are presented in Figure 5.1. The age range is broken down into several categories:

(i) 5 years and Under.

(ii) 6 - 10 years.

(iii) 11 - 15 years.

(iv) 16 - 20 years.

(v) 21 - 25 years.

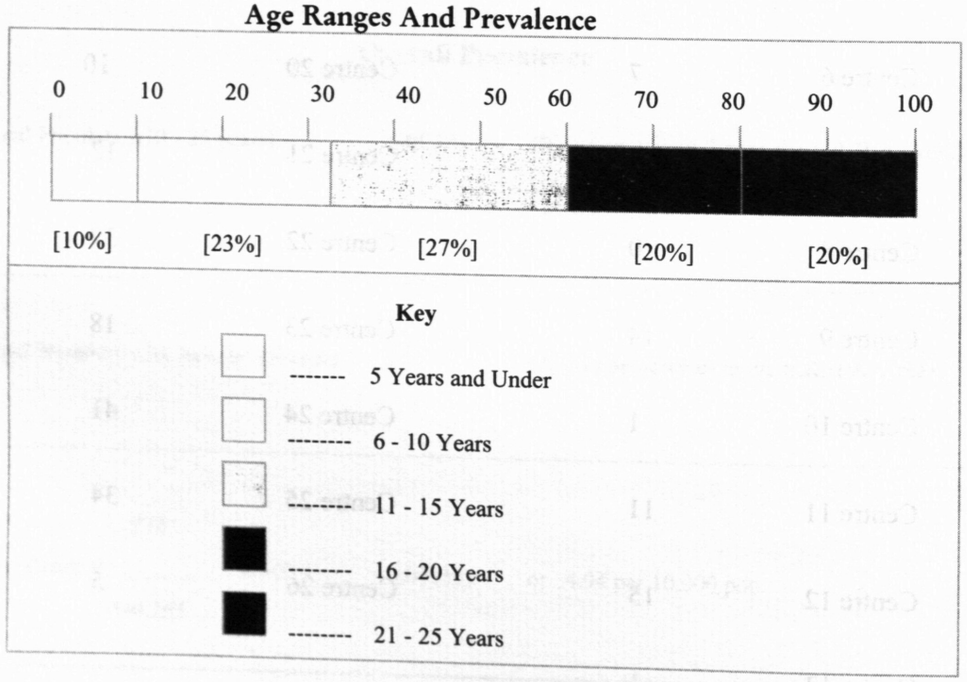

Figure 5.1: The number of subjects in the different age groups.

As can be seen from Figure 5.1 an approximately equal number of person with autism were in each of the four age groups older than age 5. There were 23% of persons with autism aged between 6 - 10 years. There was a further 27% between ages 11 - 15 years and 20% between 16 - 20 years and 21 - 25 years. Only 10% of these person identified as autistic were aged up to 5 years.

There were 204 (75%) males and 68 (25%) females with autism identified (see Figure 5.2). This constitutes a ratio of approximately three males to every one female.

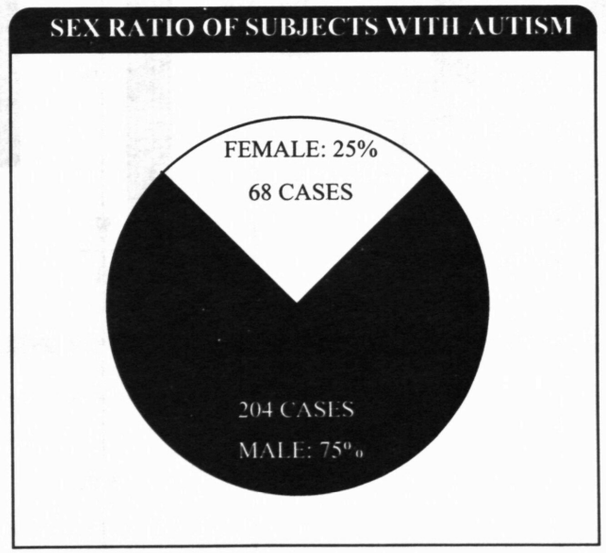

Figure 5.2: The ratio of male to female cases identified in this study.

5.2 The Age: Sex Ratio of Persons with Autism

The following figure (Figure 5.3) is a breakdown of the percentage of males and females in each age range. There is not such a large difference between the male:female ratio in the 16-20 year age range present in the other age intervals.

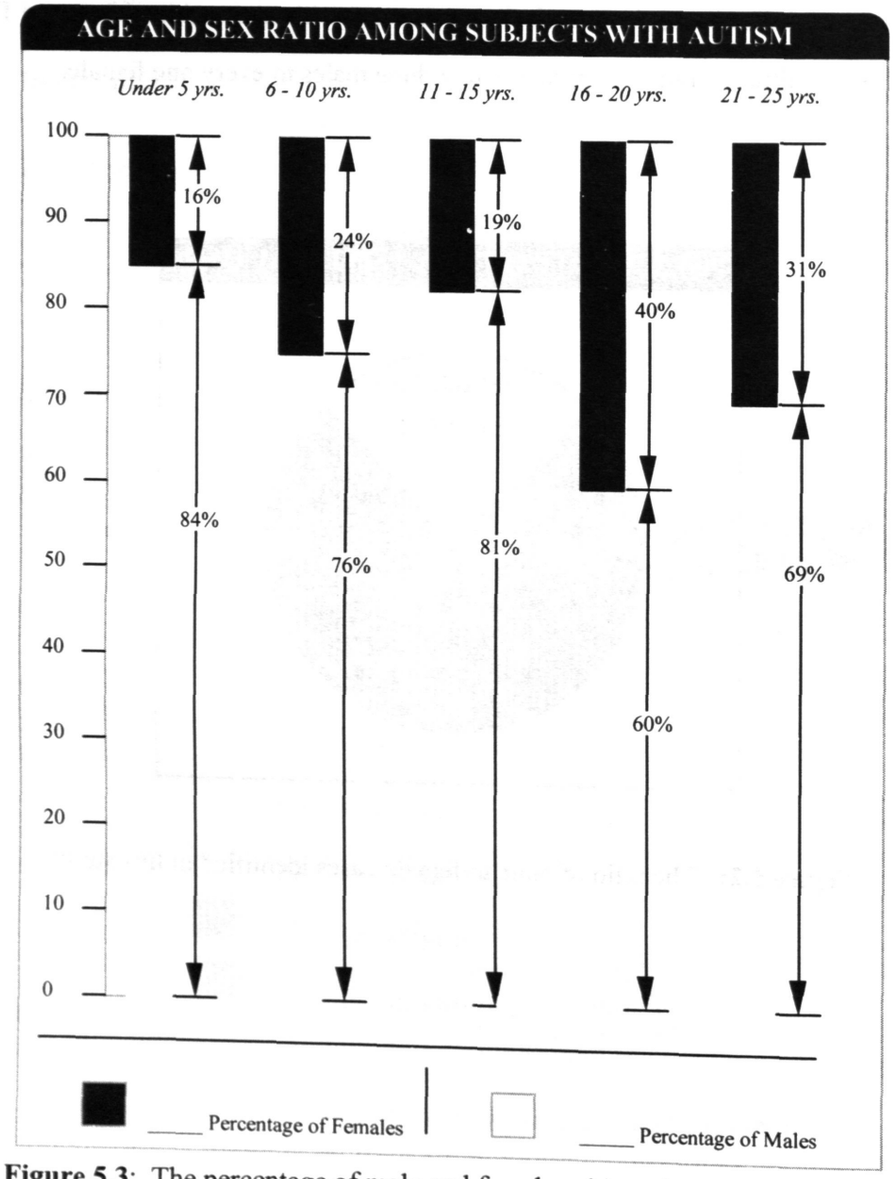

Figure 5.3: The percentage of male and female subjects in five different age groups (i) under 5 years, (ii) 6-10 years, (iii) 11-15 years (iv) 16-20 years and (v) 21-25 years (N = 272).

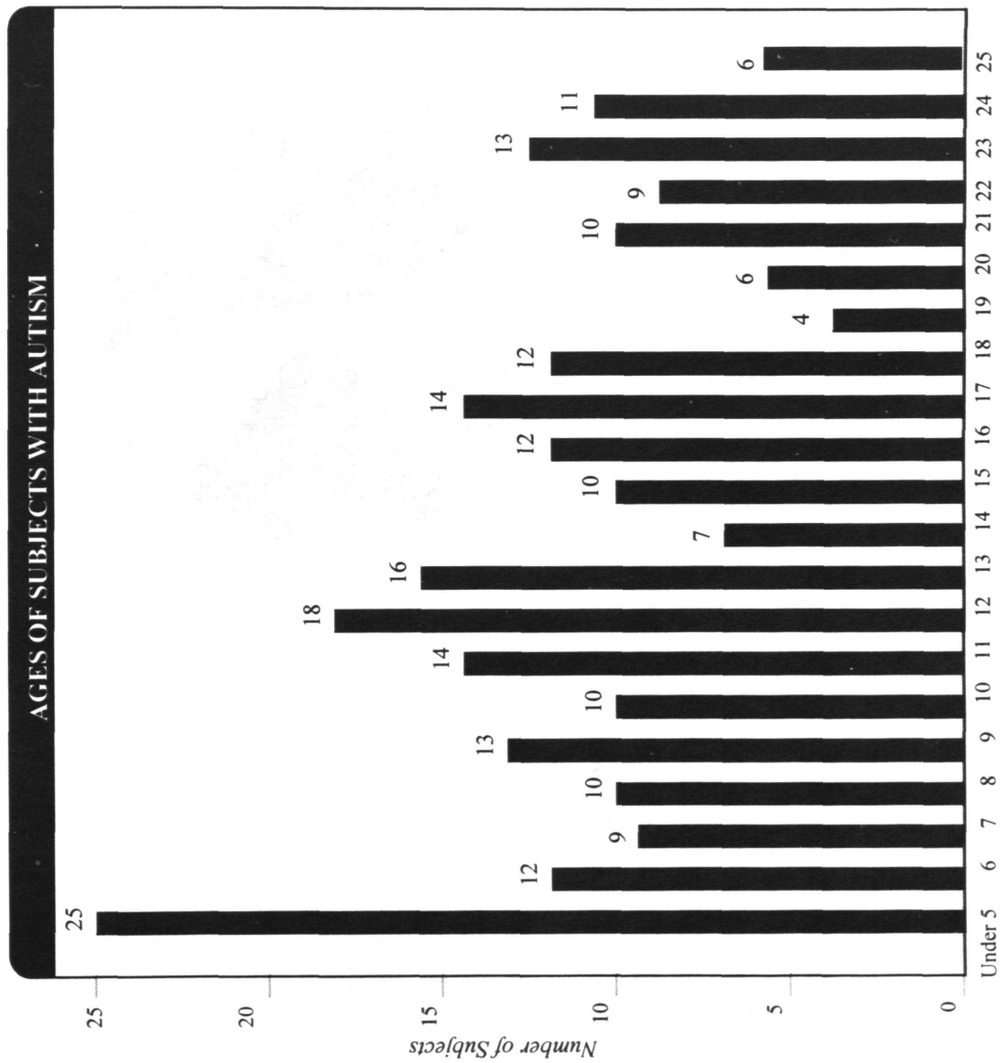

Figure 5.4: Detailed breakdown of the age ranges of the subjects with Autism.

5.3 Month and Season of Birth of Persons with Autism

The month of birth of persons with autism is presented in the following table. The profile of months of birth does not provide any support for the hypothesis of elevated rates of children with autism born in March. Of the 215 subjects for which data was available/provided, no clear disparities were evident. When the data was further analysed and examined according to season of birth (see Figure 5.5), an almost equal number of subjects was found to have been born in each of the seasons.

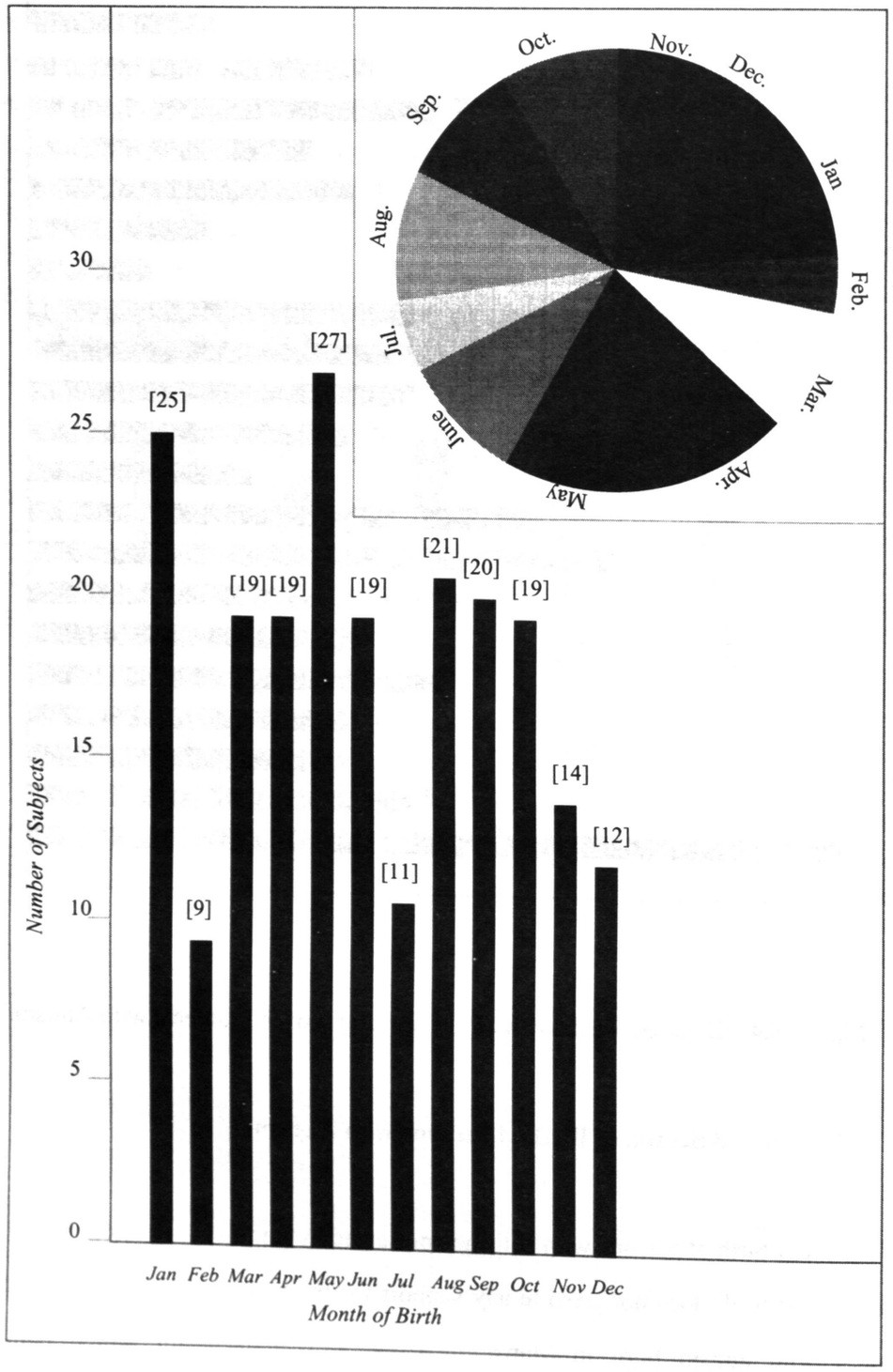

Figure 5.5: The distribution of months of birth of the subjects with autism. (N = 215)

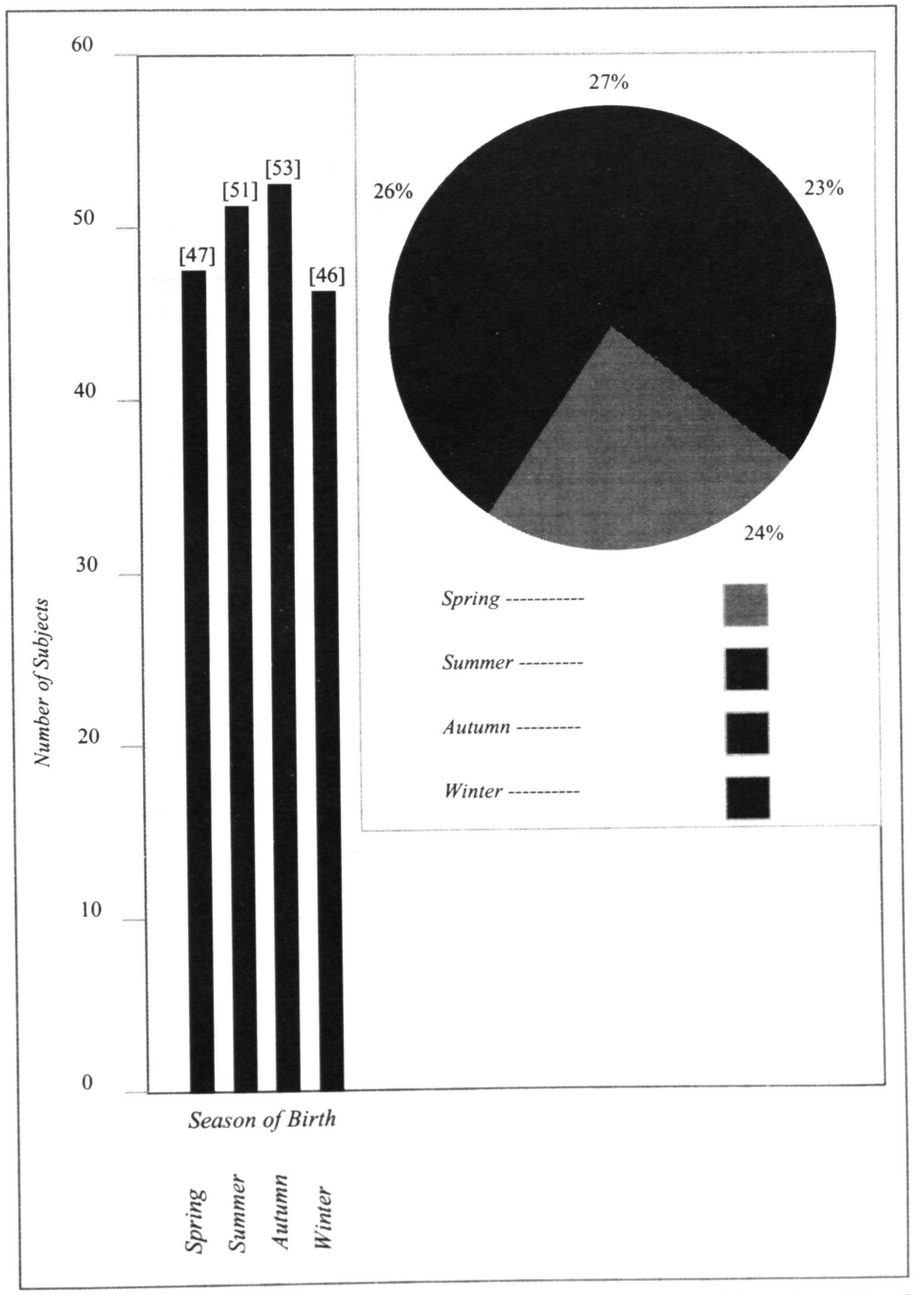

Figure 5.6: The distribution of seasons of birth of the subjects with autism (N = 215).

5.4 The Birth Order of Person with Autism

No relation between birth order and autism was found. There were no clearly disproportionate percentages of cases found to be contained in any group (First born, only

child, etc), See Figure 5.7. This information was available for 95 persons identified as autistic whose parents were also interviewed.

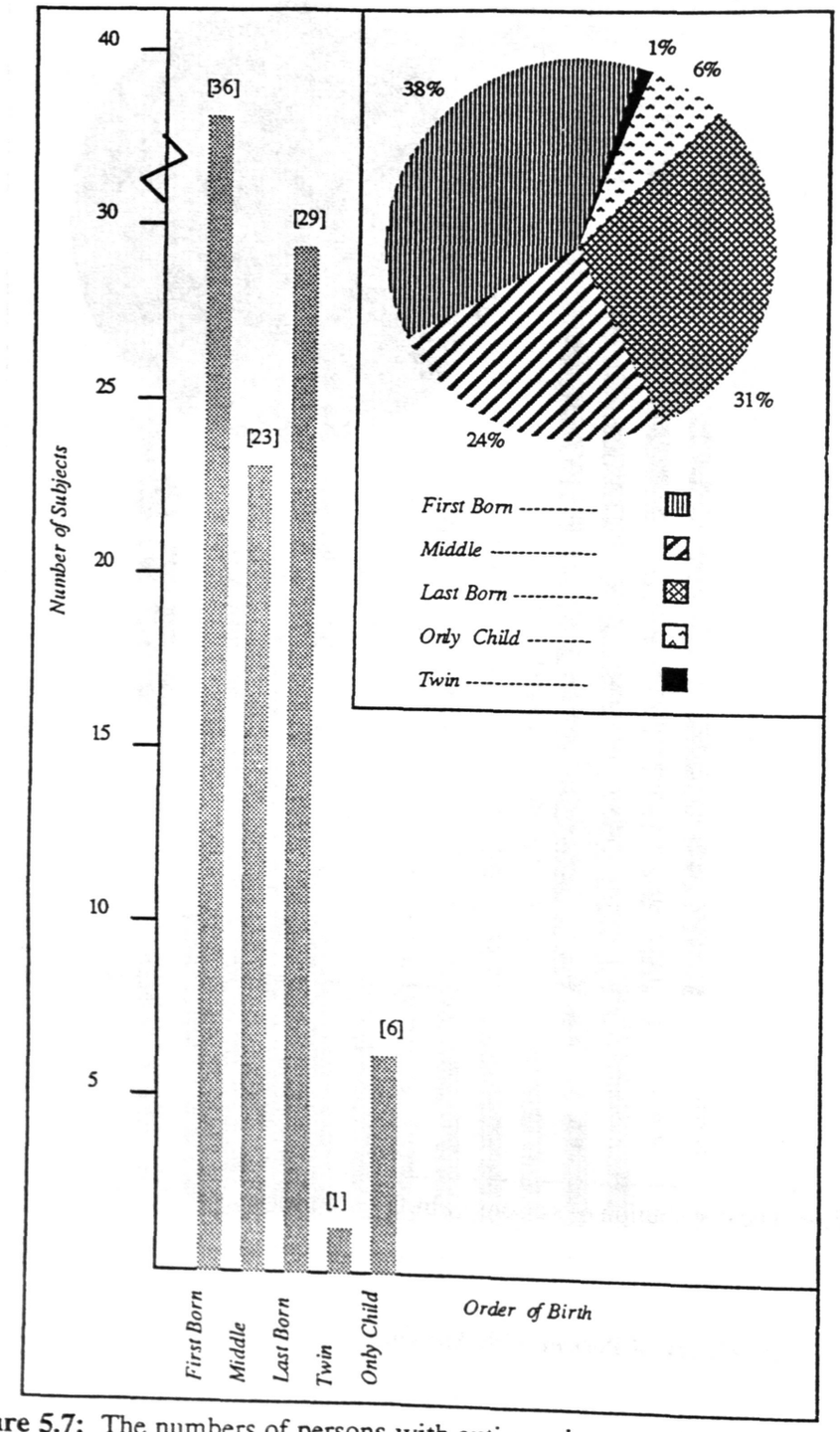

Figure 5.7: The numbers of persons with autism who were first born, middle, last born, a twin or an only child. (N = 95)

5.5 Number of Siblings of Persons with Autism

The number of siblings of persons with autism is presented in the Figure 5.8.

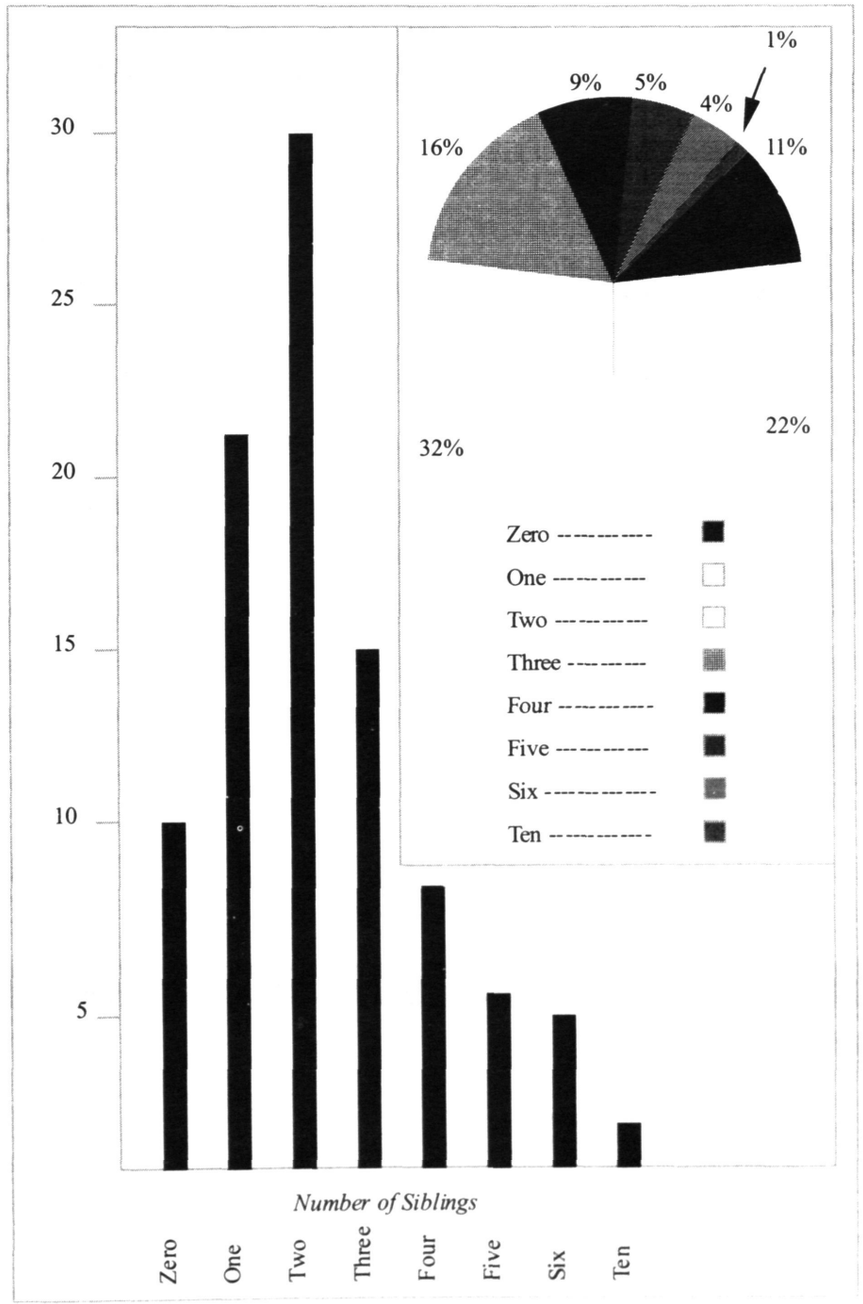

Figure 5.8: The numbers and percentages of subjects with autism having zero, one, two, three etc. siblings. (N = 94)

In relation to siblings 32% of persons with autism had 2 siblings and 22% had one sibling. (See Figure 5.8). As before this data was available for 94 persons with autism whose parents were also interviewed for this study.

5.6 Demographic Information on the Mothers of Persons with Autism

100 mothers of persons with autism were interviewed. The average age of mothers at the time of interview was 45 years (SD = 9) ranging from 27 to 67 years. The age of their children with autism was up to 25 years. The average age was 14 years (SD = 6). (Dates was missing for 15 cases).

Mothers were aged between 14 and 51 years when they gave birth to their son/daughter with autism. The average age was 32 years (SD = 7) when their child with autism was born.

The following figure (Figure 5.9) displays the marital status of the mothers interviewed. Eighty three percent (83%)of the mothers interviewed were married; 7% were separated, and 10% widowed at the time of interview.

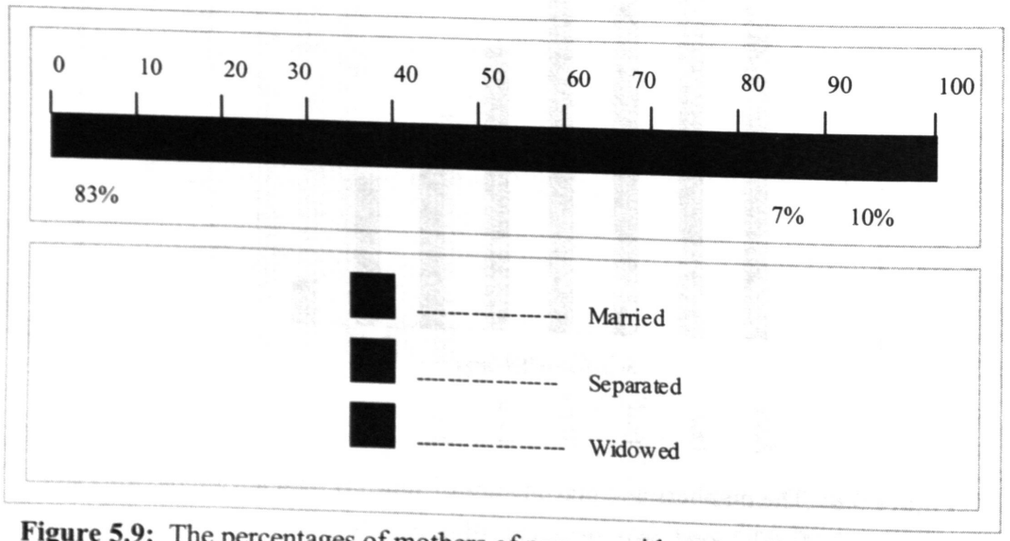

Figure 5.9: The percentages of mothers of persons with autism who were married, separated or widowed. (N = 96)

Socio-Economic Status

The following figure (Figure 5.10) is a breakdown of the socio-economic status of families with a family member who is autistic. Twenty three percent (23%) (N = 22) of the families were categorised as higher professionals in the first social class. The same number of families (N = 22) were in social class number 4 and these include intermediate non-manual workers / skilled manual workers. Eight families (8%) were in the lower professional social class, social class 2. Five percent (5%) of the families (N = 5) were in social class 3, that is salaried employees. Seventeen families (18%) were categorized as social class 5 such as non-manual workers or semi-skilled manual workers. There was nobody in social class 6, unskilled manual workers. Group 7 represented those families where the father was unemployed, on a pension, retired or receiving a disability allowance. This accounted for 10 families (11%) in this study. Group 8 accounted for those families (12%) where the mother was separated or widowed.

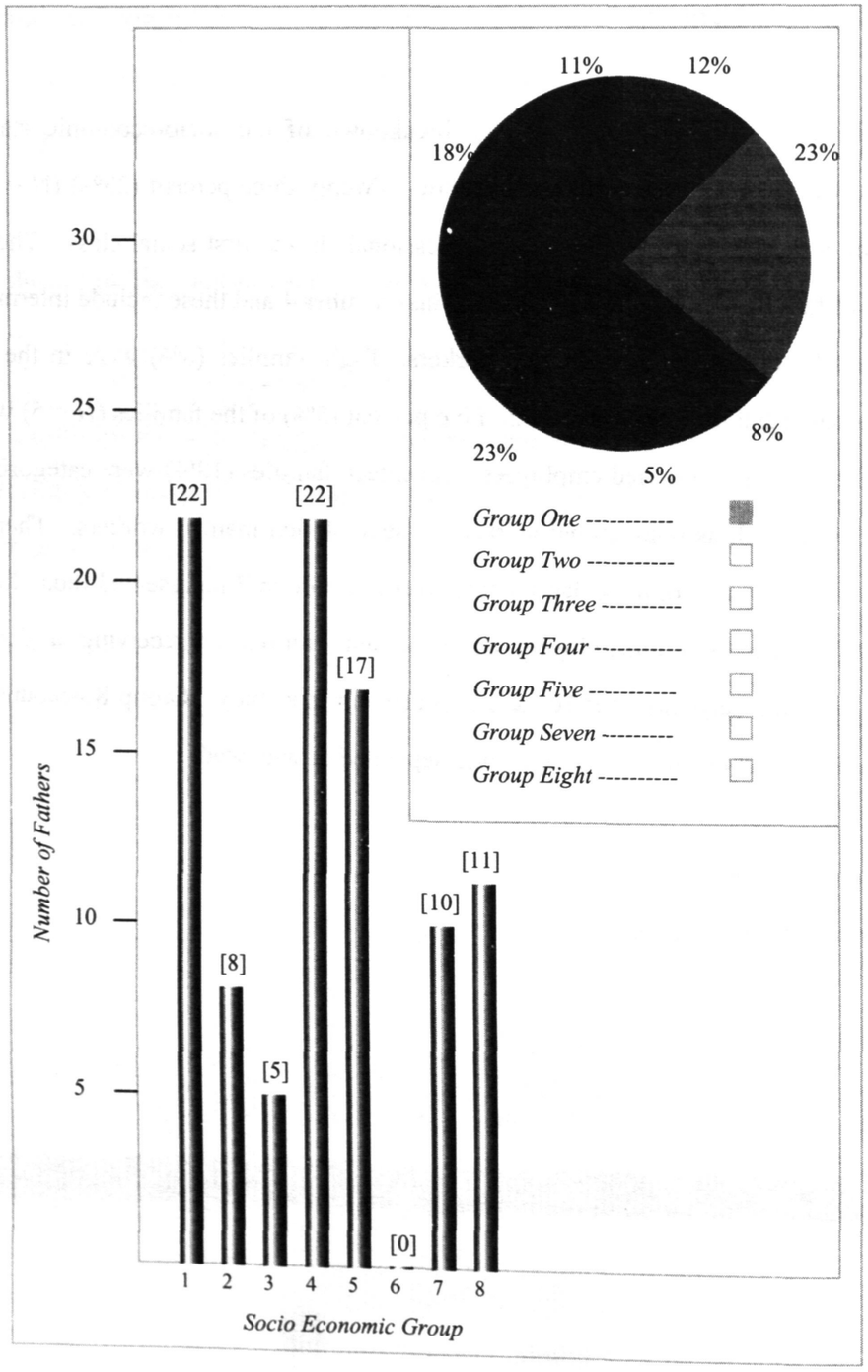

Figure 5.10: The frequency and percentages of fathers of persons with autism in each of the eight socio-economic groups (O'Hare, 1982) (N = 100).

Figure 5.11 shows a comparison of socio-economic status of parents of persons with autism in comparison to statistics of socio-economic groups for the total population of the

Eastern Region Health Authority region. These are compared with the Census for Population statistics (1991).

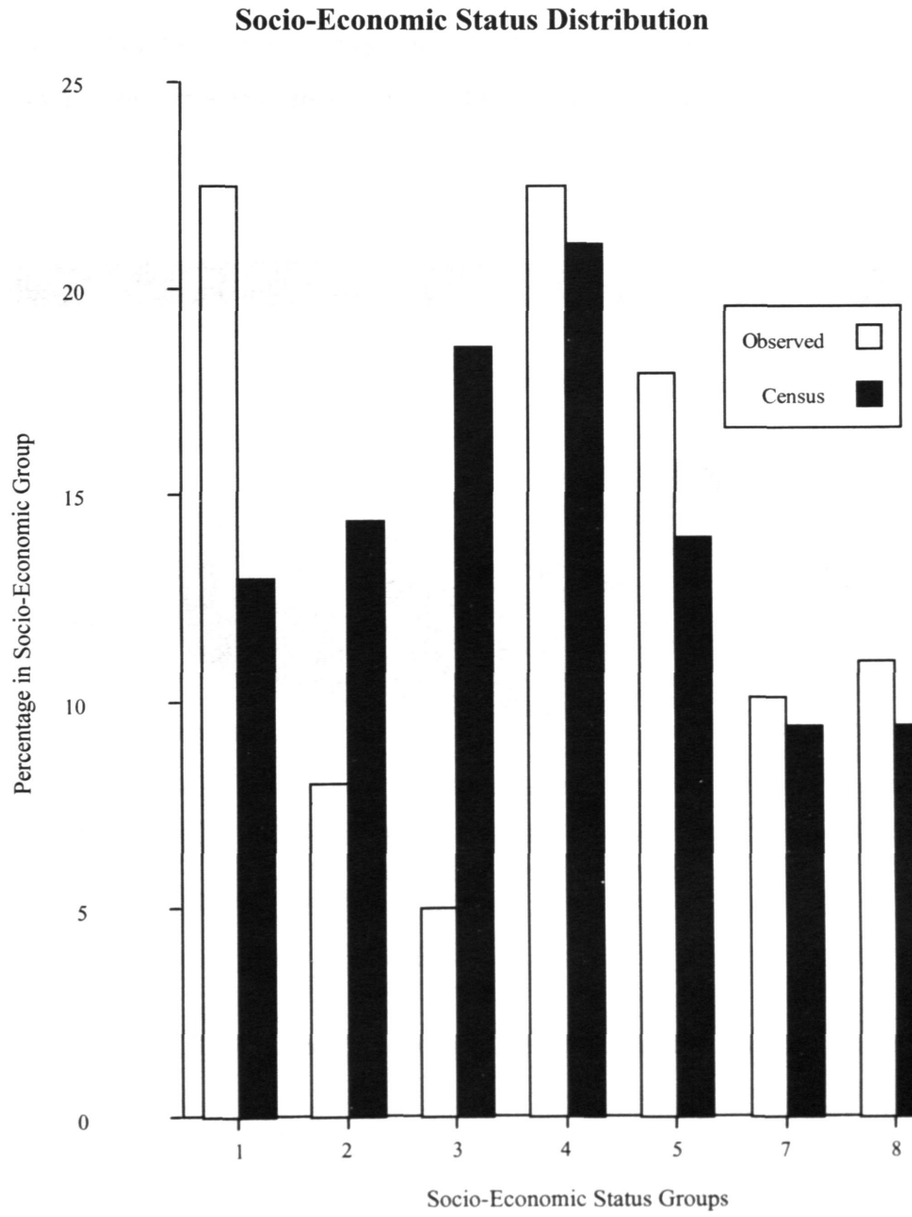

Figure 5.11: A comparison of the socio-economic group distribution for the sample of parents of persons with autism as compared to that appearing in Census of Population 1991 figures for the Eastern Region Health Authority Area.

5.7 Living Arrangements of Persons with Autism

The Figure 5.12 below shows the percentage of persons with autism living with both parents, one parent or in residential care facilities. It indicates that one quarter of subjects live in residential care (26%), the remaining three quarters were living at home, with either one parent (15%) or both parents (59%). This data represents all 272 persons identified as autistic.

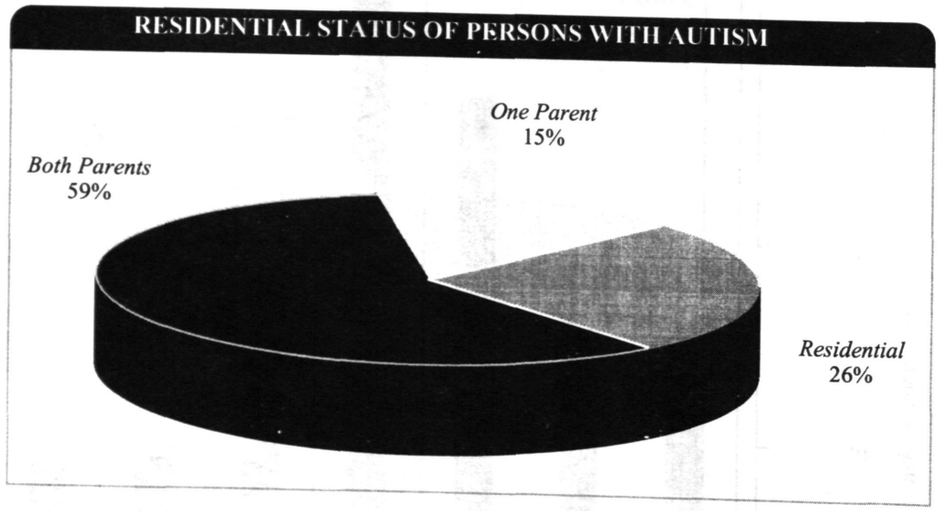

Figure 5.12: The percentage of persons with autism living with both parents, one parent, or in residential care. (N = 272)

5.8 Scoring of the Autistic Disorders Diagnostic Checklist (A.D.D.C.)

This section provides information on the scoring for each item of the A.D.D.C.. There was very considerable differences in the frequency with which individual items of the Autistic Disorders Diagnostic Checklist were rated as being present in subjects identified as having autistic disorder in this study. The items can be grouped into three groups.

(a) Group One: are individual items of the Autistic Disorders Diagnostic Checklist in which 50% or more of the persons identified with autistic disorder had these items. They include: "doesn't point out things"; "doesn't spontaneously bring toys"; "self chosen activities were solitary"; "indifferent to others; no peer friendships". (See Appendix A for a full list of items of Autistic Disorders Diagnostic Checklist and Appendix I for the percentage times they were rated as being present in persons with autism in this study.)

(b) Group Two: are individual items of the Autistic Disorders Diagnostic Checklist in which 20% - 49% of persons identified as having autistic disorder. They include: "doesn't use eye contact for attention"; "doesn't adapt posture"; "ignores visitors"; "no spontaneous imitation of others". (See Appendix A for a full list of items of Autistic Disorders Diagnostic Checklist and Appendix D for the percentage times they were rated as being present in persons with autism in this study.)

(c) Group Three: are individual items applying to 19% or less of persons identified as having autism using the Autistic Disorders Diagnostic Checklist. They include: "doesn't anticipate being held"; "invents fantasy person or world"; "no response to communication"; "swallows inedible objects". (See Appendix A for a full list of items of Autistic Disorders Diagnostic Checklist and Appendix D for the percentage times they were rated as being present in persons with autism in this study.)

Figure 5.13 shows the most commonly occurring items of the Autistic Disorders Diagnostic Checklist which persons with autism showed evidence of in this study. The most common items identified were "self chosen activities were solitary" which was coded in 87% of the persons with autism. A large proportion (75%) were said to be indifferent to others as reported by key workers and over half of the persons with autism were said to ignore others (52%). 80% of those identified had no peer friendships while

68% were reported as having no personal modesty and 65% had a lack of awareness of correct public behaviour.

Approximately half of those identified as autistic engaged in repetitive body movements (48%) for example, rocking. Thirty eight percent (38%) engaged in repetitive self injury and 20% had an unusual attachment to certain objects while 13% collected certain objects and arranged these objects in patterns. Almost all of the persons with autism identified were reported as having life styles that were restricted, empty and routine bound (84%).

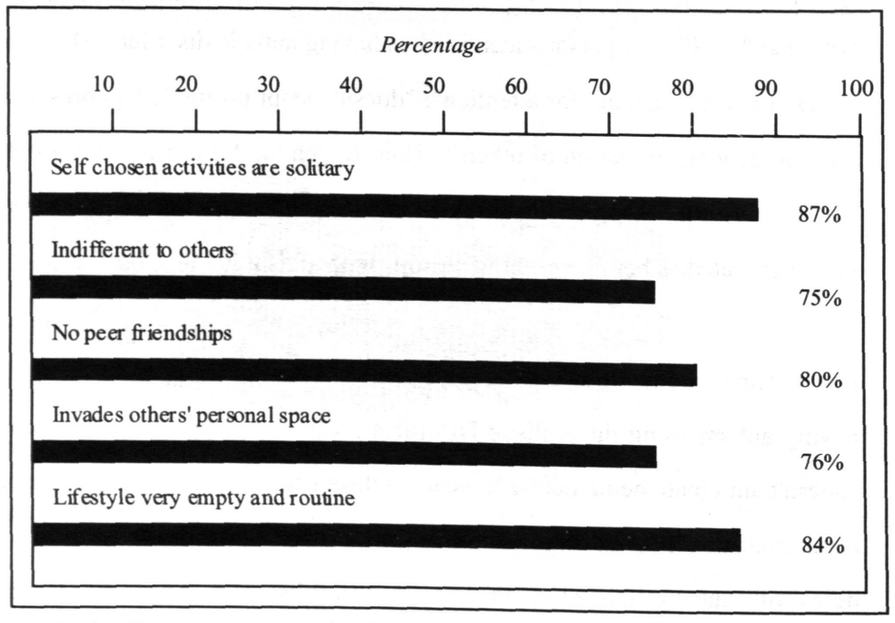

Figure 5.13: The percentages of subjects with autism scoring on five most frequently endorsed items of the Autistic Disorders Diagnostic Checklist. (N = 272)

The following three figures (5.14, 5.15, 5.16) also show the frequency of the presence of individual items taken from the three sections on the Autistic Disorders Diagnostic Checklist in persons with autism. The first figure reveals the distribution of numbers of items subjects scored on in Section A ['Impairments in Reciprocal Social Interaction'] of the Autistic Disorders Diagnostic Checklist. (N = 272) (See Appendix A for a definition of each question).

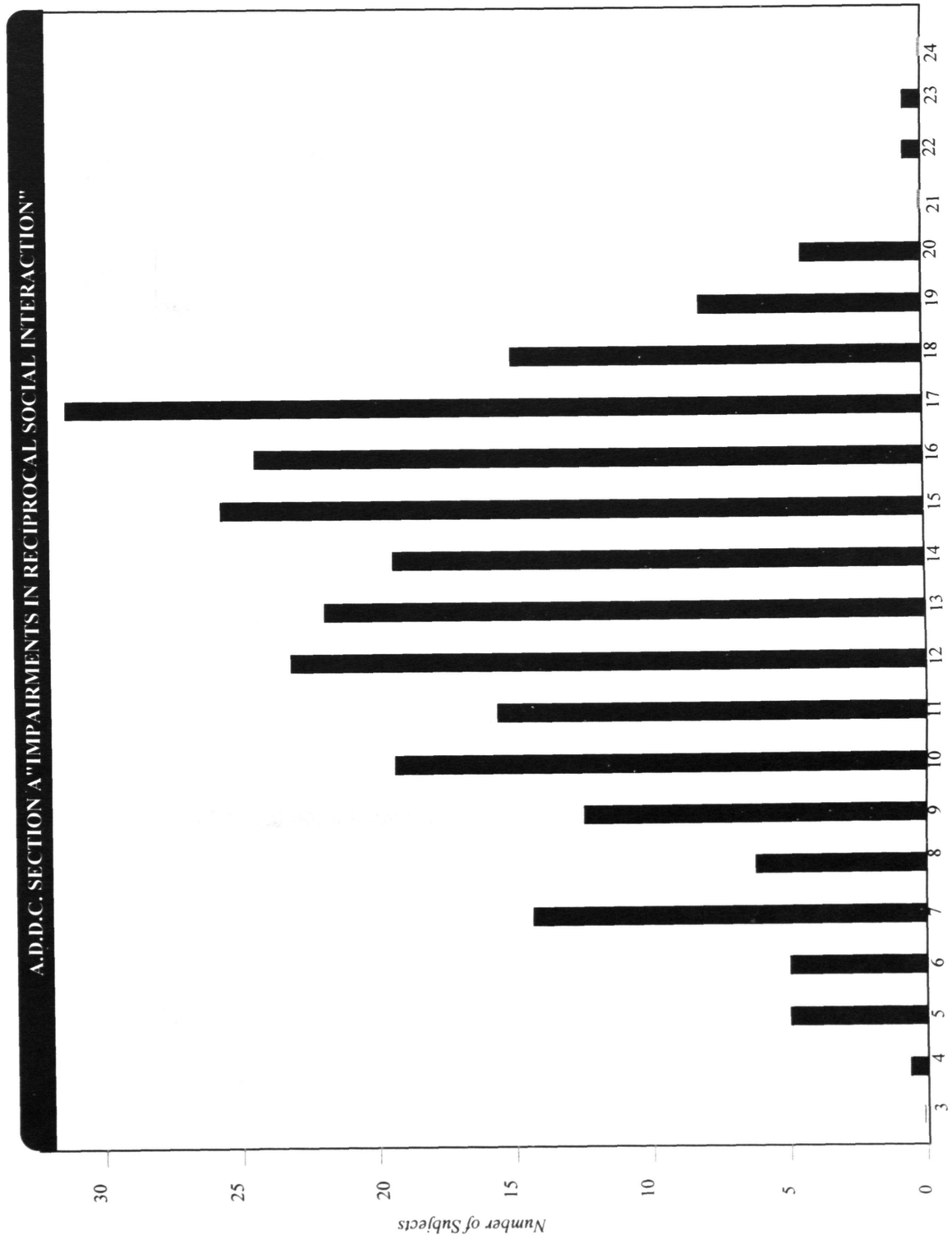

Figure 5.14: The distribution of number of items subjects scored on for Section A of A.D.D.C.

Autistic Disorders Diagnostic Checklist

The figure below shows the number of people scoring on each individual item in Section B of the A.D.D.C. (see Appendix A for a definition of each question).

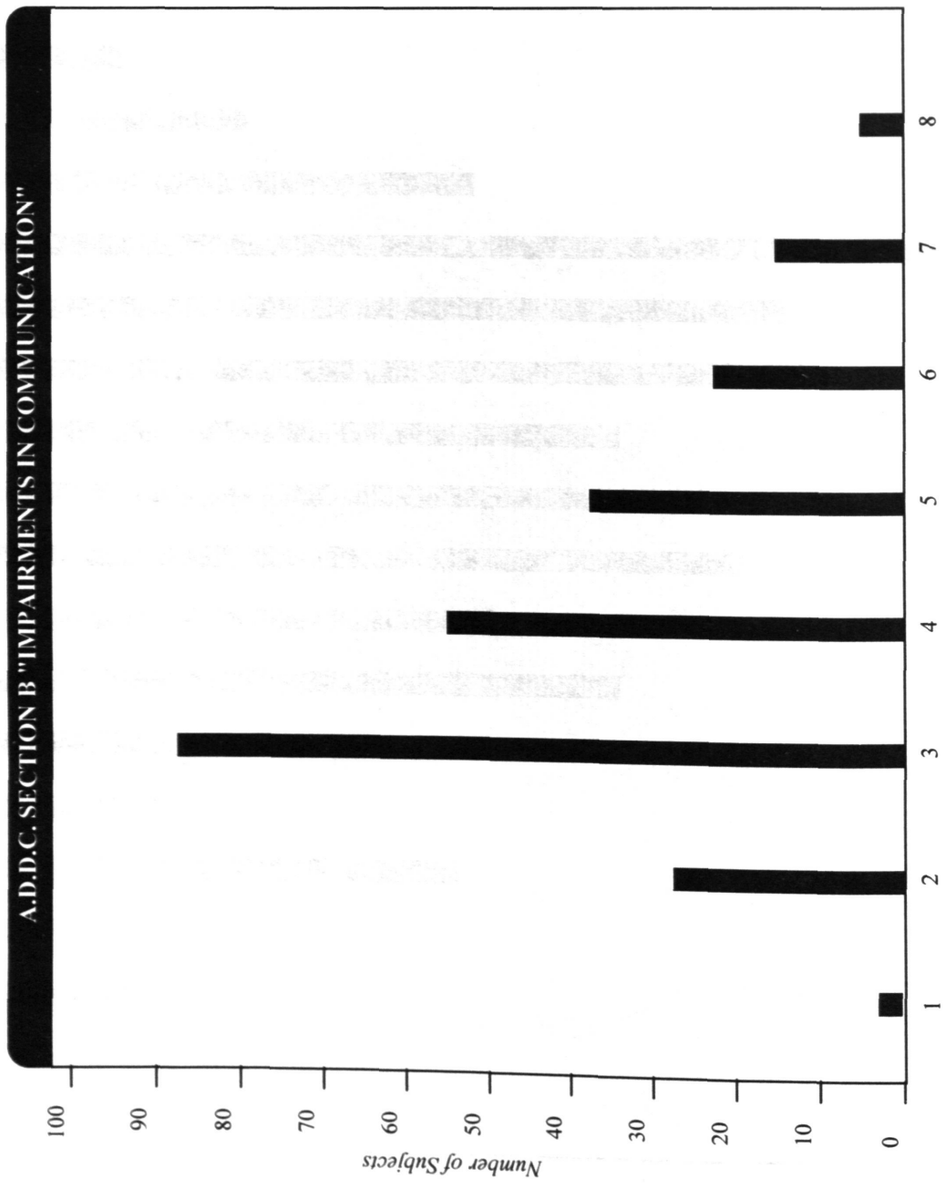

Figure 5.15: The distribution of scores in Section B of the A.D.D.C.

Figure 5.16 shows the number of people scoring on each individual item in Section C of the A.D.D.C. (see Appendix A for a definition of each item).

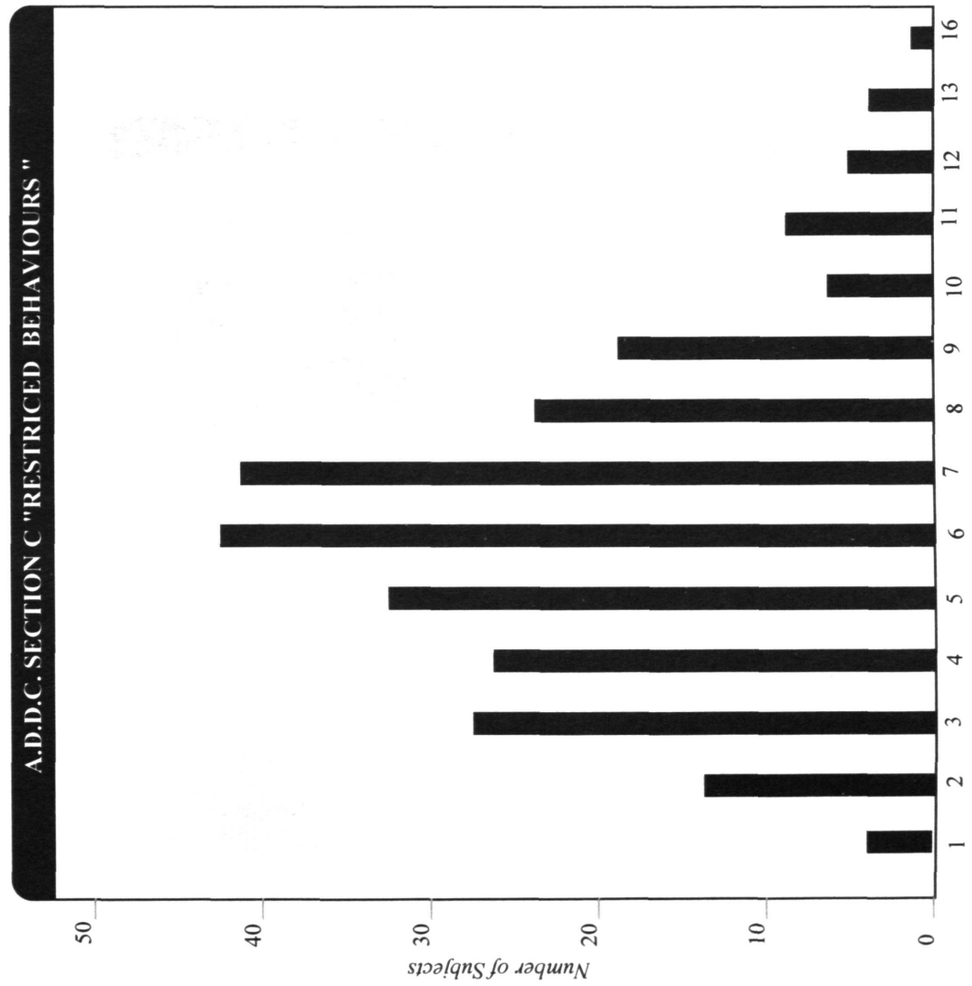

Figure 5.16: The distribution of number of items scored by persons with autism on the A.D.D.C., section C (N = 272).

The following Figure 5.17 shows the percentage of persons with autism as identified by the Autistic Disorders Diagnostic Checklist scoring at the minimum or above the minimum using the algorithm developed by Dr. Lorna Wing (1987 - Personal Communication) as described in the methods section.

The persons with autism scored above the minimum in 90% of cases with regard to reciprocal social interaction and 76% of cases with regard to repetition of activities and interests.

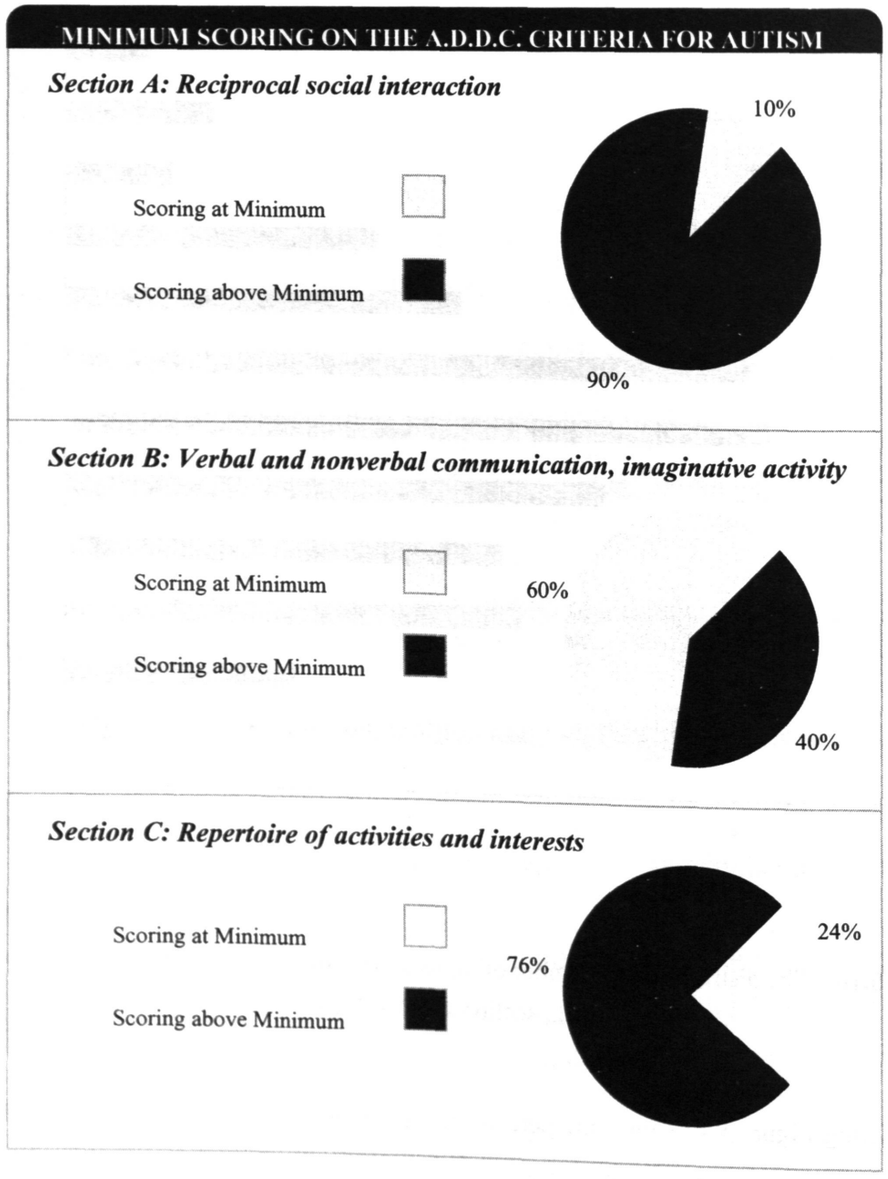

Figure 5.17: The percentages of subjects diagnosed as autistic in the present study who scored at or above the minimum requirements for this diagnosis of autism on each of the three sections of the criteria (N=272).

5.9 Diagnosis of Autism Using Different Systems of Diagnosis (See Appendix E)

Staff in the Eastern Region Health Authority (formally the Eastern Health Board) region identified 309 people as displaying "autistic tendencies". When the staff were asked to rate these individuals on the (Wing, 1987 - Personal Communication) A.D.D.C. Checklist (Appendix A) 272 persons met the criteria for autism. This A.D.D.C. checklist was revised in 1991 (Appendix E) and it was decided to investigate if the same 309 persons initially identified would meet the criteria outlined for the diagnostic categories of autism in the revised version. Different systems of diagnosing autism and related conditions use criteria that overlap but differ in detail (Wing, 1991 - Personal Communication). The A.D.D.C. checklist (Wing, 1991 - Personal Communication, see Appendix E) can be used to elicit the criteria for the following diagnostic systems. Dr. L. Wing (1995 - Personal Communication) points out "that all the conditions overlap so much that many can be put into more than one category - hence the idea of the continuum".

Dr. L. Wing (1995 - Personal Communication) points out that the revised A.D.D.C. (1991 - Personal Communication) was "substantially the same" as the A.D.D.C. (1987 - see Appendix A) except further addition of a small number of items and a change in the wording of a few others (see Appendix E).

Because there were a few additional items in A.D.D.C. (1991 - Appendix E) as opposed to A.D.D.C. (1987 - Appendix A) this could have led to a very small reduction of in those meeting alternative criteria to autism on A.D.D.C. (1987 - Appendix A).

DSM-III-R (Draft criteria - see Appendix E)

The findings are as follows: for the *DSM-III-R* draft diagnostic system 256 people (85%) out of a possible 309 met the criteria. This was slightly less than the number who met the criteria for autism on the A.D.D.C. (Wing, 1987 - Personal Communication) checklist

(N=272). Dr. L. Wing (1995 - Personal Communication) points out that "the criteria are very close to the final published ones" of DSM-III-R. The final published version of DSM-III-R (APA, 1987) titles group A as reciprocal social interaction rather than impairment in social interaction (DSM-III-R draft - Appendix E). They title group B as verbal and non-verbal communication, imaginative activity (APA, 1987) rather than impairment of communication and imagination (DSM-III-R draft - Appendix E). The DSM-III-R - draft (Appendix E) focuses on the major domains of social interaction, communication, and imagination and repetitive activities which most researchers would regard as fundamental to autism. DSM-III-R (APA, 1987) identified the same fundamental criteria but have less subgroup criteria than the DSM-III-R draft criteria (Appendix E).

ICD 10, Draft Research Criteria (See Appendix E)

Using the *ICD 10, Draft Research Criteria* - These criteria were applied to the remaining 37 people (309-272=37) who did not meet the requirements using the A.D.D.C. checklist. Only 3 people met ICD-10 draft research criteria. When all 309 persons identified in the South Western Area Health Board region as having "autistic tendencies" were included in the analysis almost half of the persons with autism (N=144, 47%) met the ICD-10 draft criteria. The ICD10 draft research criteria (Appendix E) has exactly the same onset criteria as the final published version (WHO, 1993). The ICD10 draft research criteria (Appendix E) titles group 1 as impairment of social interaction while ICD10 (WHO, 1993) titles group one as "qualitative abnormalities in reciprocal social interaction". The ICD10 draft research criteria (Appendix E) title group 2 as impairment of communication and imagination while ICD10 (WHO, 1993) define group 2 as "qualitative abnormalities in communication". ICD10 draft research criteria (Appendix E) titles groups 3 as "repetitive activities" while ICD10 (WHO, 1993) titles group 3 as "restricted, repetitive and stereotyped patterns of behaviour, interests and activities". The ICD10 draft research

criteria (Appendix E) are more elaborate than ICD10 (WHO, 1993) but identify the same fundamental concepts of autism.

Kanner's Syndrome

The Kanner's 5 Criteria Kanner & Eisenberg (1956) were applied to the 309 initial cases of persons with "autistic tendencies" identified and 24 persons (8%) met the criteria. It may be possible to account for the low number of people who met Kanner's 5 criteria for autism even though 272 persons were diagnosed as autistic using the A.D.D.C. checklist (Wing, 1987 - Personal Communication). Persons had to score in five different categories of behaviour in order to be defined as autistic according to Kanner and Eisenberg (1956), however there were only three categories in the A.D.D.C. checklist (Wing, 1987 - Personal Communication). In addition to be diagnosed as autistic using Kanner's 5 criteria a person had to demonstrate good feats of memory of skill with visuo-spatial tasks and the following behaviour (item C 3c) "arranges objects in straight lines or patterns - may be upset if arrangements are disturbed". Given that so many people with autism in the study were lower functioning not many evidenced such behaviour. In fact in this study only 13% (N=35) of persons with autism engaged in this behaviour.

There were new items introduced to the 1991 revised edition of the A.D.D.C. (Wing, 1991 - Personal Communication) checklist which were not included in the A.D.D.C. (Wing, 1987 - Personal Communication) checklist used in this study, and these are outlined in Appendix E. The other diagnoses that can be elicited using the A.D.D.C. required that these certain behaviours be present, since they were not included in the A.D.D.C. (1987 - Personal Communication) checklist, other diagnoses were conducted ignoring these extra questions. This may also partially help explain why only a few persons met Kanner's 5 criteria. This point also applies to Kanner & Eisenberg's (1956) 2 criteria, Asperger syndrome and Wing & Gould's (1979) triad of social interaction,

communication and imaginative impairment and repetitive stereotyped activities (see Appendix E).

Kanner & Eisenberg's 2 Criteria (Kanner and Eisenberg, 1956)

With regard to Kanner & Eisenberg's diagnostic categories for autism, 220 (71%) people in this study met the criteria. The remaining 89 persons (29%) did not. This finding may help explain why the numbers were low with regard to Kanner's 5 criteria, that is, when the number of criteria necessary for diagnosis were reduced a greater number were diagnosed as autistic.

Asperger Syndrome

Nobody met the criteria for Asperger Syndrome. It may be possible to explain why this occurred. Criteria for diagnosis were very strict as was the case for Kanner's 5 criteria. In order to score everybody had to evidence the following behaviour (item C 6c or item C 6d).

6c Preoccupied with special interests dependent on good rote memory, ability to calculate, or musical ability (e.g. time tables; routes to places; calendars; arithmetical calculations; computers; games depending on numbers; the music of a specific composer).

6d Preoccupied with particular subjects; tends to amass facts but usually lacks depth of understanding (e.g. methods of transport; meteorology; genealogy of royal families; the legends of King Arthur; military uniforms; specific imaginary or real people. The subjects may be lurid or frightening, such as details of murders or monsters from outer space).

Of the 272 persons identified using the A.D.D.C. checklist (Wing, 1987 - Personal Communication) only 11% (N=30) scored on item 6c and even less scored item 6d (N=19, 7%).

Additionally, in order to be diagnosed using Asperger criteria persons also had to show the following behaviour (item A 1f) 'Does make social approaches, but does not use variations in eye to eye gaze, etc., or vocalizations such as 'um' or 'ah' to punctuate conversations and to guide turn taking'. Only 11 (4%) persons from 272 displayed this behaviour.

From the above it is possible to see why nobody met all five criteria for Asperger syndrome.

Wing & Gould's (1979) triad of social interaction, communication and imagination impairments as well as repetitive, stereotyped activities

A large proportion of people from the initial 309 identified met the criteria for Wing & Gould's triad of social interaction, communication and imagination (N=239, 77%). Unlike Kanner's 5 criteria or Asperger criteria there was a much broader spectrum of behaviour included in Wing & Gould's triad of social, communication and imagination impairments as well as repetitive stereotyped activities making it more likely that a person would meet the criteria.

5.10 Sex Differences in Relation to Individual Items of the Autistic Disorders Diagnostic Checklist

There were a number of statistically significant differences between the frequencies of individual items of the Autistic Disorders Diagnostic Checklist for male and female

persons with autism. These included abnormality in pitch, lack of awareness of social appropriateness, social indifference and passivity in play as can be seen in Table 5.3.

Table 5.3: The items of the Autistic Disorders Diagnostic Checklist for which significant differences were found to exist between male and female subjects with autism.

Item of Autistic Disorders Diagnostic Checklist	Level of Significance (p)	Predominance among males or females?
1) 'Abnormality in pitch, stress, rate, rhythm or intonation'	.04	More frequently appearing among female subjects
2) 'Lack of own awareness for need for personal modesty'	.05	More frequently among males
3) 'Indifferent to others'	.005	More frequently among males
4) 'Passive role in play'	.02	More frequently among males

There was greater abnormality of pitch in the female persons with autism. Males had a greater lack of awareness for the need for personal modesty than females. Males also showed greater indifference to others and took a more passive role in play than female persons with autism.

5.11 Findings from the Interviews with Mothers of Persons with Autism

The interviewer also administered a series of questionnaires to the mothers. These were identified in the Method section. They include the:

(i) Vineland Maladaptive Behaviour Scale.

(ii) Index of Social Competence.

(iii) Family Burden Questionnaire.

(iv) Social Problem Questionnaire.

(v) General Health Questionnaire.

Mothers were also asked to complete another qualitative questionnaire, which inquired about issues relating to the diagnosis of their son or daughter as having autism, the age of their son or daughter when they were diagnosed as having autism etc. (See Appendix C).

The Vineland Maladaptive Behaviour Scale and the Index of Social Competence are concerned with the persons with autism, their level of dependency and abilities. The Family Burden Questionnaire, the Social Questionnaire and the General Health Questionnaire pertain to the family and mother. The scores for the Vineland Maladaptive Behaviour Scale are presented first followed by the Social Competence Scale.

The Vineland Maladaptive Behaviour Scale is divided into two sections: Part 1 and Part 2. Part 1 describes minor maladaptive behaviours while Part 2 describes more serious maladaptive behaviours . The scoring ranges from 0 (behaviour not present), 1 (sometimes present), 2 (yes usually). In this study the total score was computed by summing scale 1 + 2, a high score indicated more maladaptive behaviours. The mean overall score was 27.80 (SD = 10) ranging from 3 to 47. In Section 1 the mean score was 21.84 (SD = 8) ranging from 2 to 38. In Section 2 the average score was 6.2 (SD = 3) ranging from 0 - 14.

This scale can only be used for children aged 5 or over. The number who responded to this questionnaire was 82, the findings are presented in Table 5.4 and Table 5.5.

Over half of individuals with autism were rated by their mothers as being overly dependent (55%) and a similar percentage (54%) were reported to be withdrawn. Similarly 53% were reported as exhibiting extreme anxiety, 60% of those with autism demonstrated behavioural tics while 54% cried or laughed too easily. With regard to eye contact the findings were evenly divided, there was equal number who demonstrated poor eye contact (37%) and those who did not have poor eye contact (37%). The remainder (26%) sometimes demonstrated poor eye contact. A large number of persons with autism were also described by their mothers as being very impulsive (53%).

Quite a large number of persons with autism sometimes or a lot of the time exhibited temper tantrums (70%). Furthermore approximately one half (48%) of persons with autism were physically aggressive at sometime. Similarly 50% were negativistic or defiant and a total of 26% teased or bullied others. Others (15%) displayed inappropriate social behaviour by swearing in the wrong situation, a further 6% sometimes displayed this behaviour. Based on the mother's report 21% of those with autism try to run away regularly while 13% sometimes display this behaviour.

Few persons with autism demonstrated other minor maladaptive behaviours, for example only 8% sucked their thumb, 10% bit their nails, 8% lied, cheated, or stole things, 11% avoided their school work and 12% ground their teeth. Approximately a quarter had problems with bed wetting (21%), eating (27%) and sleeping (20%). According to the mothers 20% of persons with autism displayed excessive happiness and a further 22% sometimes displayed this behaviour.

A large number of persons with autism were reported as having poor concentration (67%) and a similar percentage (63%) as overactive. In addition 62% were reported by their mothers as lacking consideration for others. Just over a half of those with autism were reported as being stubborn or sullen (52%) by their mothers.

Table 5.4: The scores for the Vineland Maladaptive Behaviour Scale - Part 1[1].

	No	Sometimes	Yes Usually
Sucks thumb or fingers	68 (83%)	6 (7%)	8 (10%)
Is overdependent	28 (34%)	9 (11%)	45 (55%)
Withdraws	21 (25%)	17 (21%)	44 (54%)
Wets bed	56 (69%)	8 (10%)	17 (21%)
Exhibits an eating disturbance	47 (57%)	13 (16%)	22 (27%)
Exhibits a sleep disturbance	41 (50%)	25 (30%)	16 (20%)
Bites fingernails	74 (90%)	-	8 (10%)
Avoids school or work	67 (82%)	6 (7%)	9 (11%)
Exhibits extreme anxiety	19 (23%)	20 (24%)	43 (53%)
Exhibits tics	17 (21%)	16 (19%)	49 (60%)
Cries or laughs to easily	21 (25%)	17 (21%)	44 (54%)
Has poor eye contact	30 (37%)	22 (26%)	30 (37%)
Exhibits excessive unhappiness	48 (58%)	18 (22%)	16 (20%)
Grinds teeth during day or night	59 (72%)	13 (16%)	10 (12%)
Is too impulsive	29 (35%)	10 (12%)	43 (53%)
Has poor concentration or attention	15 (18%)	12 (15%)	55 (67%)
Is overactive	21 (26%)	9 (11%)	52 (63%)
Has temper tantrums	25 (30%)	17 (21%)	40 (49%)
Is negativistic or defiant	41 (50%)	19 (23%)	22 (27%)
Teases or bullies	61 (74%)	9 (11%)	12 (15%)
Shows lack of consideration*	22 (27%)	9 (11%)	50 (62%)
Lies, cheats or steals	72 (88%)	3 (4%)	7 (8%)
Is too physically aggressive*	42 (52%)	26 (32%)	13 (16%)
Swears in inappropriate situations	65 (79%)	5 (6%)	12 (15%)
Runs away	54 (66%)	11 (13%)	17 (21%)
Is stubborn or sullen	26 (32%)	13 (16%)	43 (52%)
Is truant from school or work	78 (95%)	3 (4%)	1 (1%)

* 1 case is missing

Looking at the more serious maladaptive behaviours in part 2 only a small number of persons with autism demonstrated inappropriate sexual behaviour (17%). As would be

[1] Valid percentages are presented for persons with autism aged 5 years and over (N=82).

expected a large number of persons with autism (67%) demonstrated excessive or peculiar preoccupation with objects/activities. Similarly many demonstrated unusual habits/mannerisms (56%). Only a small number expressed thoughts that were not sensible (22%). Persons with autism also demonstrated self-injurious behaviour (30%). Only a small number intentionally destroyed property (16%), used bizarre speech (12%) or were unaware of their immediate surroundings (8%). Over a quarter demonstrated rocking behaviour (28%).

Table 5.5: The scores for the Vineland Maladaptive Behaviour Scale - Part 2.

	No	Sometimes	Yes Usually
Engages in inappropriate sexual behaviour*	56 (69%)	11 (14%)	14 (17%)
Has excessive or peculiar preoccupation with object or activities*	15 (18%)	12 (15%)	54 (67%)
Expresses thoughts that are not sensible*	62 (77%)	1 (1%)	18 (22%)
Exhibits extremely peculiar mannerisms or habits*	23 (28%)	13 (16%)	45 (56%)
Displays behaviours that are self-injurious*	44 (54%)	13 (16%)	24 (30%)
Intentionally destroys own or another's property*	61 (75%)	7 (9%)	13 (16%)
Uses bizarre speech*	69 (85%)	2 (3%)	10 (12%)
Is unaware of what is happening in immediate surroundings*	65 (80%)	10 (12%)	6 (8%)
Rocks back and forth when sitting or standing*	46 (57%)	12 (15%)	23 (28%)

* 1 case is missing

5.12 Social Competence of Persons with Autism

Mothers were asked to rate their son/daughters level of competency in the areas outlined in the following table 5.6. The scale was devised by McConkey and Walsh (1982). There are 15 subscales and each subscale consists of three, four or five items; all of which could be easily and frequently observed in everyday circumstances. These are arranged in order of difficulty. The most difficult item is given first and this is the one which only a small percentage of mentally handicapped adults would be capable of passing. The last item is the easiest in that nearly all would pass it. The social competence scores of persons with autism age 8 years or over are presented. The number of cases was 67 persons with autism. The findings are based on the mothers responses.

As can be seen from Table 5.6 the majority of persons with autism had normal vision (96%) and hearing (90%). The majority (78%) did not suffer from fits (epilepsy) although 9% had fits (epilepsy) that was considered problematic, and a further 13% had non-problematic fits (epilepsy). The majority of those persons with autism had poor communication skills, for example, 76% could only follow very simple instructions. Only 12% could speak well, intelligible to all people. While almost a third (30%) had no speech or gesture.

Table 5.6: Social Competence Scores for those age 8 and over. [2]

Vision	Normal	96%	
	Partial	3%	Total
	Blind	1%	100%
Hearing	Normal	90%	
	Partial / aid	7%	Total
	Deaf	3%	100%

[2] Valid percentages are presented for persons with autism aged 8 years and over for whom the Index of Social Competence is suitable (N=67).

Epilepsy	No fits	78%	
	Fits - but not a problem	13%	Total
	Fits - problematic	9%	100%
Instructions	Remember and carry out sequence instructions	9%	
	Remember instructions	5%	
	Follow simple instructions	76%	Total
	No response except to name	10%	100%
Communication	Speaks well	12%	
	Lack clarity in speech	32%	
	Difficulty in speech	26%	Total
	No speech / gesture	30%	100%
Eating	Feed self	67%	
	Feed self with help	18%	
	Feed self - alot of help	12%	Total
	Needs to be fed	3%	100%
Personal Needs	Independent	31%	
	Requires checking and reminding	37%	
	Has to be helped	17%	Total
	Dependent on others	15%	100%
Mobility Level	Able walk, run, climb	91%	
	Walk - difficulty running climbing	8%	Total
	Walk only short distances	1%	100%
Use of Hands	Competence in use of hands	39%	
	Manage most activities	34%	
	Slow, clumsy use hands	25%	Total
	Very basic hand skills	2%	100%
Around the House	Capable most jobs	33%	
	Needs supervision	9%	
	Does simple repetitive jobs	21%	
	Attempts simple jobs	28%	Total
	Unable to do jobs around house	9%	100%

Prepare Food	Prepare variety of meals	6%	
	Prepare simple hot food	7%	
	Prepare food with no cooking	45%	
	Simple food with supervision	18%	Total
	All food has to be prepared	24%	100%
Reading ability	Read and follow instructions	12%	
	Can read signs	15%	
	Recognise written name	16%	
	Pick out food names	24%	Total
	Can't recognise writing	33%	100%
Writing Ability	Write short notes	18%	
	Write name and address	6%	
	Write names	2%	
	Copy name / address	19%	Total
	Unable to write	55%	100%
Understand Time	Full understanding of time	9%	
	Tell time from clock / watch	4%	
	Knows hour by clock	8%	
	Anticipate some events	30%	Total
	No idea of time	49%	100%
Understand Money	Use money responsibly	2%	
	Know right amount	2%	
	Some idea of money	4%	
	Know coins by name	13%	Total
	No understanding of money	79%	100%

Most responses indicated that persons with autism were quite dependent in self-care skills. While 67% were able to feed themselves the remainder needed help (30%) or had to be fed (3%). Barely a third (31%) were independent in the area of personal needs. 15% were completely dependent on others to look after their personal needs while the remaining half needed help or some form of checking or reminding (54%).

The majority of persons with autism were completely mobile (91%) and the majority had competent use of hands or could manage most activities (73%).

Regarding their ability to do tasks around the house only a third (33%) were capable of most jobs, while a fifth (21%) could do simple repetitive jobs. These findings highlight the dependency and need for supervision of those with autism in this study. This point is further reinforced in the findings for 'food preparation'. Only 6% could prepare a variety of meals, however almost a half (45%) could prepare food that did not involve any cooking. In addition 24% needed all their food to be prepared for them.

When it came to reading and writing skills and the ability to understand time and money persons with autism in this study were again quite dependent.

79% of those with autism had no understanding of money. Almost one half (49%) had no idea of time. While 30% could anticipate some events only 9% had a full understanding of time.

Reading and writing skills were also very poor, only 12% could read and follow instructions while 33% could not recognise any writing at all. Similarly only 18% could write short notes and 55% were unable to write anything. However 19% could copy their own name and / or address.

The social competence scale can be broken down into four areas:

(i) Additional handicaps (ii) Communication skills

(iii) Self care skills (iv) Community skills

A score equal to or greater than the median in all four areas places the person in the high ability range (McConkey and Walsh, 1982). A score lower than the median in all four areas indicates low ability range. Other combinations indicates a mixed ability. The mean score, standard deviation (SD) and range of scores in the four areas just outlined are presented in the following Table 5.7.

Table 5.7: Social Competence Areas

Area	Mean	SD	Range
Additional handicaps	3.5	0.84	3 - 7
Communication skills	5.6	1.5	2 - 8
Self care skills	12.84	4.14	6 - 21
Community skills	15.76	4.5	4 - 20

The majority of person with autism in this study were found to be in the mixed ability range (N=62, 93%) and a very small number were classified as having 'low ability' (N=5, 7%).

5.13 The Levels of Burden Experienced by Families

As mentioned earlier mothers were also asked to report on the problems and burdens experienced due to having to care for a son / daughter with autism. The findings of the Family Burden Interview (1981) are presented first followed by the Social Questionnaire and the General Health Questionnaire.

The Pai and Kapur Family Burden Interview (1981) was used to assess the burden placed on families of persons with autism living at home. This measure is a semi structured interview schedule focussing on various areas of burden including:

(i) Financial.

(ii) Effect on family routine activity.

(iii) Effect on family leisure.

(iv) Effect on family interaction.

(v) Effect on physical health of other family members.

(vi) Effect on mental health of other family members.

Each item within each area of burden could be recorded as absent (scored zero), moderate (scored 1) or severe (scored 2). The findings for each item in the various areas of burden are presented in the following tables.

The majority of those interviewed (85%) were not burdened by the fact that their son / daughter with autism did not bring an income into the household. In many cases persons with autism were still of school going age and not expected to be contributing to the family financially. 79% of those interviewed had incurred extra expenses because of their son / daughter's autism. Overall there was considerable burden experienced by the families of persons with autism, expenses were incurred by 60% of mothers due to extra arrangements having to be made for their son / daughter and 40% of mothers were financially burdened because of loans taken out for their son / daughter with autism.

Table 5.8: The financial burden of having a person with autism

	N	No Burden	Moderate Burden	Severe Burden
Loss of patients income	94	85%	9%	6%
Loss of other family members income	98	39%	38%	23%
Extra expenditure incurred	98	21%	41%	38%
Extra care giving arrangements expenditure	98	40%	41%	19%
Loans taken out	98	60%	26%	14%
Cancel activities due to financial pressure	98	59%	25%	16%

Mothers were asked a series of questions relating to the various areas of burden just mentioned and they were then asked to indicate the extent of the burden.

Having a person with autism effected family routine as can be seen from Table 5.9. 80% of the mothers reported a moderate or severe burden if their son / daughter missed a day at school or their normal daily activity. Activities of other family members were also greatly disrupted (74%). The behaviour of the person with autism had a moderate or severe effect on routine family activities for 65% of those interviewed. Just under half of the respondents (46%) felt that they neglected other family members due to the burden of having a child with autism (combining moderate and severe).

Table 5.9: The effect of having a person with autism on family routine activities

	N	No Burden	Moderate Burden	Severe Burden
Inconvenience of person with autism missing day activity, school or other activity	98	20%	20%	60%
Person with autism not helping in household work	98	74%	20%	6%
Disruption of activities of other family members	98	26%	34%	40%
Behaviour of person with autism disrupting routine activities	98	35%	21%	44%
Neglect rest family due to person with autism	97	54%	29%	17%

Table 5.10: The disruption of family leisure due to persons with autism

	N	No Burden	Moderate Burden	Severe Burden
Stopping recreational activities	98	28%	35%	37%
Using up other family member's holiday time	97	37%	33%	30%
Person with autism led to a lack of attention to other family members	96	55%	32%	13%
Cancel a leisure activity	98	33%	41%	26%

As can be seen from the Table 5.10 family leisure was effected because of the person with autism. Leisure activities were often cancelled (67%), normal recreational activities were also effected and the reaction of other family members to this was a burden for almost three quarters (72%) of the respondents. The lack of attention to other family members by the person with autism was a considerable burden for almost half of the families. Many mothers interviewed reported family burden (63%) because holiday time was taken up by their son / daughter with autism (combining moderate and severe ratings).

Table 5.11: The disruption of family interaction due to person with autism

	N	No Burden	Moderate Burden	Severe Burden
Ill effect on atmosphere in home	96	43%	31%	26%
Arguments over person with autism	96	55%	28%	17%
Visitors stopped calling	98	53%	28%	19%
Family became secluded	97	47%	34%	19%
Effect on relationships in family	96	53%	33%	14%

As can be seen from Table 5.11 there was an ill effect on the general atmosphere in the house and just over a quarter of the mothers interviewed (26%) felt that this was a severe burden. Just under one half of the families (45%) felt moderate or severe burden regarding other family members arguing over the person with autism. 19% reported severe burden regarding how the family felt when visitors stopped calling. Over half (53%) felt that the family had become secluded and this was a source of burden for them. Similarly half of the families (47%) were burdened because the person with autism had effected relationships within the family.

Table 5.12: The effect on physical health of others due to person with autism

	N	No Burden	Moderate Burden	Severe Burden
Family member suffered physical ill health	97	58%	26%	16%
Adverse effect on health	97	55%	26%	20%

When asked had any other members of the family suffered physical ill health and how had this effected them 26% reported moderate burden while 16% said it was a source of severe burden. The findings were similar when asked had there been any other adverse effect on health, for example, someone losing weight or an existing illness being exacerbated.

Table 5.13: The effect on mental health on others due to person with autism

	N	No Burden	Moderate Burden	Severe Burden
Family member sought psychological help	97	47%	34%	19%
Lost sleep, became depressed, weepy	96	27%	56%	27%

The mental health of the family also suffered. Over half (53%) of the respondents reported seeking some form of psychological help. Considerable burden, both moderate and severe, was also experienced by 83% of the respondents regarding loss of sleep, depression and irritability (etc.) due to caring for a person with autism in the family home.

5.14 The Social Problem Questionnaire

The Social Problem Questionnaire is a short 31-item self-report questionnaire identifying social problems, difficulties and dissatisfaction. It covers areas such as:

(i) Housing,
(ii) Occupation,
(iii) Finance,
(iv) Social and leisure activities,
(v) Child, parent and marital relationships,
(vi) Relationships with relatives, friends, neighbours and workmates, and
(vii) Legal problems.

This questionnaire is used to screen individuals in primary care or in related settings who are particularly at risk for manifesting social maladjustment and/or dysfunction. The Social Problem Questionnaire is mainly concerned with obtaining a reasonable estimate of respondents social and personal satisfaction. The individual items are rated on a 4-point scale which ranges from '0' indicating satisfactory adjustment, to '3' indicating very poor adjustment and/or severe difficulties.

The first two questions regarding 'Housing' was answered by 97 mothers. A relatively small number of mothers (n=10, 10%) experienced marked or severe problems with their housing conditions in relation to their families needs. In the second question regarding accommodation 8% of the mothers were markedly or severely dissatisfied with their

present accommodation while the majority of respondents reported satisfaction with their accommodation (78%) and 13% were slightly dissatisfied with their accommodation.

Table 5.14: Response of mothers to the Social Problem Questionnaire regarding their housing situation.

		Adequate	*Slightly Inadequate*	*Markedly Inadequate*	*Severely Inadequate*
Are your housing conditions adequate for you and your family's needs?	N=97	78%	11%	7%	3%
		Satisfied	*Slightly Dissatisfied*	*Markedly Dissatisfied*	*Severely Dissatisfied*
How satisfied are you with your present accommodation?	N=97	78%	13%	5%	3%

The next section of the Social Problem Questionnaire was concerned with the mother's occupation/social role. Twenty-one mothers responded to this section as they were also working. The majority of the respondents were satisfied with their present job (86%), while 14% were slightly dissatisfied with their job. Mothers were also asked if they experienced any problems getting on with their workmates. As before the majority of mothers (90%) had no problems, while 5% had slight problems and another (5%) had marked problems.

Mothers were asked how satisfied they were being a housewife, 56 responded. Thirty six mothers (64%) were satisfied being a housewife, 17 mothers (30%) were slightly dissatisfied with this situation while 3 mothers (5%) were markedly dissatisfied being a housewife. For those mothers who were working and running a home only eight were slightly dissatisfied with this situation.

In the next section regarding 'Finances' 97 mothers responded. There were three individual questions in this section. A significant number had financial problems, for

example, 12% of the mothers interviewed reported that the money coming into the household was markedly or severely inadequate in order to meet family needs. Just over half the mothers regarded their finances as adequate (56%) and the remainder felt that finances were slightly inadequate. In the second question regarding finances a similar number of mothers (13%) reported having severe or marked difficulties meeting their bills or other financial commitments. Only half of the mothers interviewed reported that they were satisfied with their financial position (49%) the remainder were slightly (38%), markedly (8%) or severely (4%) dissatisfied with their financial position.

Table 5.15: Response of mothers to the Social Problems Questionnaire regarding their finances, the amount of time the mother has to go out and problems with neighbours.

Is the money coming in adequate for you and your family's needs		*Adequate*	*Slightly Inadequate*	*Markedly Inadequate*	*Severely Inadequate*
	N=97	56%	32%	9%	3%
Do you have any difficulties in meeting bills and other financial commitments?		*No Difficulties*	*Slight Difficulties*	*Marked Difficulties*	*Severe Difficulties*
	N=97	52%	35%	10%	3%
How satisfied are you with your financial position?		*Satisfied*	*Slightly Dissatisfied*	*Markedly Dissatisfied*	*Severely Dissatisfied*
	N=97	49%	38%	8%	4%
How satisfied are you with the amount of time you are able to go out?		*Satisfied*	*Slightly Dissatisfied*	*Markedly Dissatisfied*	*Severely Dissatisfied*
	N=97	61%	25%	11%	3%
Do you have any problems with your neighbours?		*No Problems*	*Slight Problems*	*Marked Problems*	*Severe Problems*
	N=97	78%	13%	4%	4%

97 mothers also responded to the section on social activities and relationships. There were four questions in this section. The first question was concerned with how satisfied mothers were with the amount of time they had to go out. 14 mothers (14%) were markedly or severely dissatisfied with the amount of time they had to go out. 59 (61%) were satisfied with the amount of time they had to go out while a quarter of the mothers interviewed were only slightly dissatisfied with the amount of time they were able to go out. Answers for the second question revealed that the majority of mothers (N=76, 78%) did not have any problems getting on with their neighbours. A small number had slight problems (N=13, 13%) while the remaining 8 mothers had marked (N=4, 4%) or severe (N=4, 4%) problems with their neighbours.

The third question queried whether mothers experienced problems getting on with their friends. The majority of mothers (N=86, 89%) did not have any problems in this area. Nine mothers (9%) experienced slight problems getting on with their friends while the remaining two mothers (2%) experienced marked problems.

The fourth question asked mothers if they were satisfied with the amount of time they got to see their friends. Just over half were satisfied (N=58, 60%), 25 mothers (26%) were slightly dissatisfied, 12 (12%) were markedly dissatisfied and two (2%) were severely dissatisfied with the amount of time they got to see their friends.

Table 5.16: Response of mothers to the Social Problem Questionnaire regarding their relations with their friends and close relatives.

		No Problems	*Slight Problems*	*Marked Problems*	*Severe Problems*
Do you have any problems getting on with any of your friends?	N=97	89%	9%	2%	

		No Problems	*Slight Problems*	*Marked Problems*	*Severe Problems*
How satisfied are you with the amount of time you see your friends?	N=97	60%	26%	12%	2%

		No Problems	*Slight Problems*	*Markedly Dissatisfied*	*Severely Dissatisfied*
Do you have any problems getting on with any close relative (including in laws or grown-up children)?	N=96	82%	13%	5%	

		Satisfied	*Slightly Dissatisfied*	*Markedly Dissatisfied*	*Severely Dissatisfied*
How satisfied are you with the amount of time you see your relatives?	N=96	70%	19%	10%	1%

The next question was concerned with any problems mothers may have experienced getting on with their relatives. There were two questions in this section and 96 mothers responded. The majority of the respondents did not experience problems with their relatives (N=79, 82%), twelve mothers (13%) experienced slight problems while five mothers (5%) experienced marked problems with their relatives.

The majority of mothers were satisfied with the amount of time they got to see their relatives (N=67, 70%); 18 mothers (19%) were slightly dissatisfied in this regard while eleven mothers (11%) were markedly or severely dissatisfied with the amount of time they got to see their relatives.

A slightly smaller number of mothers (N=92) responded to the section regarding relations with their partner. The findings for the 6 questions in this area are presented below.

Only a small number of mothers reported slight (N=6, 7%) or marked (N=4, 4%) difficulties confiding in their partners. Very few mothers reported any sexual problems in their relationship. The majority (N=85, 92%) had no problems, 2 mothers (2%) experienced slight problems, 4 (4%) experienced marked problems while only 1 mother (1%) reported severe sexual problems in her relationship with her partner. Similarly the majority did not experience any problems getting on together (N=81, 88%). The remainder reported slight (N=7, 8%) or marked problems (N=4, 4%) getting on with their partner.

Table 5.17: Response of mother to the Social Problems Questionnaire regarding their relationship with their partner.

		No Difficulties	*Slight Difficulties*	*Marked Problems*	*Severe Difficulties*
Do you have difficulty confiding in your partner?	N=92	89%	7%	4%	

		No Problems	*Slight Problems*	*Marked Problems*	*Severe Problems*
Are there any sexual problems in your relationship?	N=92	92%	2%	5%	1%

		No Problems	*Slight Problems*	*Marked Problems*	*Severe Problems*
Do you have any other problems getting on together?	N=92	88%	8%	4%	

		Satisfied	*Slightly Dissatisfied*	*Markedly Dissatisfied*	*Severely Dissatisfied*
How satisfied in general are you with your relationship?	N=92	90%	7%	2%	1%

		No	*Sometimes*	*Often*	*Yes, planned or recent separation*
Have your recently been so dissatisfied that you have considered separating from your partner?	N=92	95%	4%		1%

In general the majority of mothers were satisfied with their relationship with their partner (N=83, 90%). A small proportion were slightly dissatisfied (N=6, 7%), 2 mothers (2%) were markedly dissatisfied and 1 mother (1%) was severely dissatisfied with her relationships in general. Four mothers (4%) sometimes considered separating from their partner as they were so dissatisfied with their relationship. One mother (1%) had planned to separate from her partner. The remainder (N=87, 95%) had not considered separation.

The final question in this section was directed to those who were not married or did not have a steady relationship, 10 mothers responded to this question. Three mothers (30%) were satisfied with this situation, 5 mothers (50%) were slightly dissatisfied, 1 mother (10%) was markedly dissatisfied and another mother (10%) was severely dissatisfied.

Mothers were asked to indicate if they had any problems coping with their other younger children under 18 years; 10 mothers responded and the remainder said that this question was not applicable (N=73) or else the data was missing (N=17). Of those who did respond 3 mothers had no difficulties with their children, 5 mothers were experiencing slight difficulties and the remainder had marked (N=1) or severe (N=1) difficulties with their other children. In this same section regarding social problems that may be experienced with other children in the family mothers were asked to report on their satisfaction with their relationship with their children. Thirty-one mothers said that this question was not applicable and data was missing for 8 respondents. Findings are presented for the 61 mothers who answered this question. A large proportion of mothers reported that they were satisfied with their relationships with their other children (N=42, 69%). Approximately one-quarter of the mothers (N=14, 23%) were slightly dissatisfied with this relationship. The remaining responses revealed that the mothers were either markedly (N=4, 6%) or severely (N=1, 2%) dissatisfied with their relations with their other children. The third question in this section asked mothers if their children of school age were having any problems at school; 59 mothers responded to this question and for the majority their young children were not experiencing any school problems (N=44,

75%). Nine mothers (15%) reported slight problems and the remaining 6 reported marked (N=4, 7%) or severe problems (N=2, 3%). (Thirty-two mothers said that this question was not applicable and data was missing for 9 mothers).

The next section concerned mothers domestic relationships, that is, it was directed at those who had other adults living with them (including relatives and adult children but excluding spouse). A total of twenty-five mothers responded to the three questions in this section (valid percentages are reported for the mothers who responded). Firstly mothers were asked about any problems with regard to sharing household tasks. The majority (N=18, 72%) reported no problems in this regard, 6 mothers (24%) reported slight problems and only one mother (4%) reported marked problems. Secondly mothers were asked if they had any other difficulties with other adults in the household. Again the majority reported no difficulties (N=20, 80%), and 4 mothers reported slight difficulties (16%). As with the last question only one mother (4%) had marked difficulties in this regard. Finally mothers were asked about their satisfaction with regard to having other adults in the household, the majority (N=18, 72%) were satisfied with this arrangement. Six mothers were slightly dissatisfied (24%) and one mother (4%) was markedly dissatisfied with their domestic relationships.

Mothers were also asked whether they had any problems concerning legal matters. The majority of respondents had no problems (N=93, 96%). Two mothers (2%) reported having slight problems and another two mothers (2%) reported marked legal problems.

There were two questions in the Social Problems Questionnaire concerned with those living alone. Nine mothers responded to the first question regarding difficulties experienced by mothers living and managing on their own. Two mothers (22%) had no difficulties in this regard while 4 mothers (44%) were experiencing slight difficulties. The remainder reported marked difficulties (N=1, 11%) or severe difficulties (N=2, 22%) living on their own. There were eight respondents to the second question when mothers

were asked about their satisfaction with living on their own. Two mothers (25%) were satisfied and another 2 were slightly dissatisfied (25%). The other mothers were markedly dissatisfied (N=3, 38%) or severely dissatisfied (N=1, 12%) living and managing alone.

Finally mothers were asked if they were experiencing any other social problems. There were 97 respondents to this question and the majority did not have any other problems to report (N=93, 96%), while 2 mothers (2%) were experiencing other slight social problems and 2 mothers (2%) were experiencing severe social problems.

5.15 Health of Mothers of Persons with Autism

Mothers interviewed were asked to complete the General Health Questionnaire (30 item). The General Health Questionnaire (GHQ) was designed to be a self-administered screening test aimed at detecting psychological stress among respondents in community settings such as primary care. Each item consists of a question asking whether the respondent has recently experienced a particular symptom or item of behaviour on a four point scale ranging from "less than usual" to "much more than usual".

In this study the scale is treated as a bimodal response scale (score 0 or 1) so that only pathological deviations from normal signal possession of the item. This is a very simple method of scoring, and has the advantage that it eliminates any errors due to "end-users" and "middle-users", since they will score the same. A score of 5 was the cut off score used.

The average score on the GHQ was 5.098 (SD = 6.520) ranging from 0 to 26. Fifty-eight mothers scored below the cut off score of 5, while 34 mothers scored 5 or above. There were 8 missing cases. The scores of 30 individual items on the GHQ are presented in the following table (Table 5.18). As can be seen from the table (Table 5.18) almost half of the mothers interviewed reported that they were constantly under strain (43%). A large

proportion of mothers reported that they were (1) taking things hard (30%) (2) they were experiencing restless and disturbed nights (29%), and (3) they were losing sleep over worry (24%), and that (4) they felt everything was getting on top of them (29%).

Approximately a quarter of the mothers had problems concentrating (26%), while 19% said they were losing confidence in making decisions. Indeed 22% of the mothers said they were "getting panicky for no reason at all".

On the other hand almost all of the mothers interviewed 91% were able to face up to their problems; 83% were hopeful about the future and 88% were feeling reasonably happy. 92% were managing to keep busy and 91% managing as well as most would do "in their shoes".

Table 5.18: Scores of Mothers of Persons with Autism on the General Health Questionnaire (N=92)

	N	No Problem Experienced	Problem Experienced
Concentration ability	**92**	74%	26%
Loose sleep over worry	**92**	76%	24%
Restless disturbed nights	**92**	71%	29%
Managing to keep busy	**91**	92%	8%
Getting out as much as usual	90	78%	22%
Managing as well as most in your shoes	92	91%	9%
Feeling were doing things well	92	88%	12%
Satisfied way carried out tasks	91	84%	16%
Feel warmth and affectionate to others	92	94%	6%
Easy to get on with people	**92**	87%	13%

	N	No Problem Experienced	Problem Experienced
Chat to people	92	87%	13%
Playing useful part	92	92%	8%
Able to decide things	92	84%	16%
Constantly under strain	89	57%	43%
Not able to overcome difficulties	89	81%	19%
Finding life a struggle	89	75%	25%
Able to enjoy things	89	80%	20%
Taking things hard	89	70%	30%
Getting panicky for no reason	89	78%	22%
Able to face up to problems	88	91%	9%
Everything on top of you	89	71%	29%
Feeling unhappy	89	80%	20%
Losing confidence in yourself	89	81%	19%
Think yourself worthless	89	92%	8%
Finding life entirely hopeless	89	93%	7%
Hopeful about own future	88	83%	17%
Feeling reasonably happy	89	88%	12%
Feeling nervous and strung up	89	81%	19%
Felt life not worth living	89	93%	7%
Do nothing, nerves too bad	88	89%	11%

A number of mothers appeared to be experiencing alot of problems, for example 22% were not getting out as much as usual. In fact 7% of mothers interviewed were finding life entirely hopeless and not worth living, while 8% thought of themselves as worthless.

To investigate these findings further the mothers were divided into two groups. Group 1 comprised those who scored below the cut off score of 5, these were called the "good psychological health mothers". Group 2 were termed the "poor psychological health mothers" and they all scored 5 or more on the General Health Questionnaire suggesting stress.

92 mothers completed the General Health Questionnaire. A total of 34 mothers (37%) were found to be in "poor psychological health" since they scored 5 or more on the General Health Questionnaire. The remaining 58 mothers (63%) were considered to be "good psychological health" since they all scored below 5. (Data was missing for 8 cases).

The following figure (Figure 5.18) reveals the scores on the General Health Questionnaire for mothers of persons with autism.

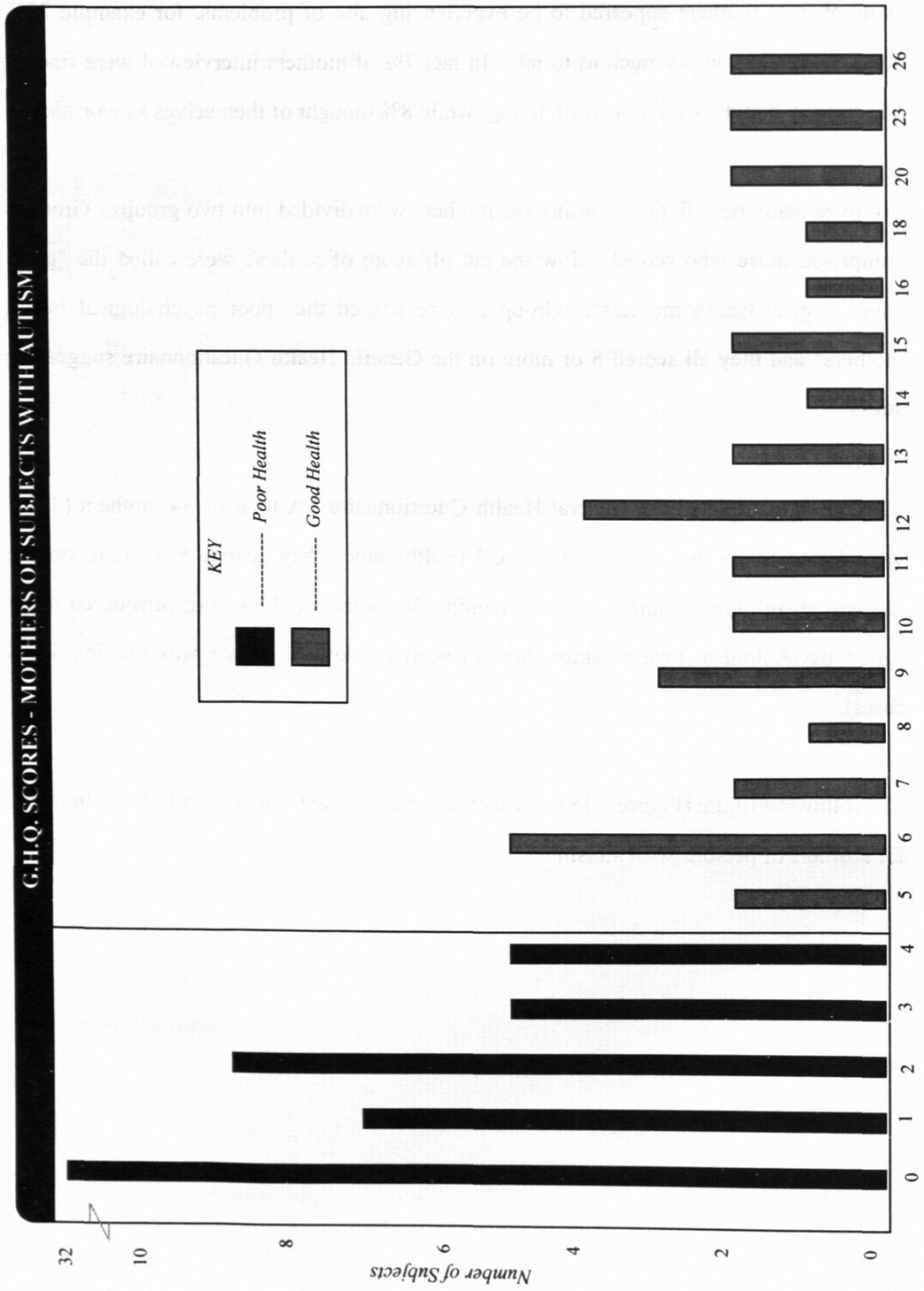

Figure 5.18: The health status of the mothers of persons with autism gained from the scores obtained in the General Health Questionnaire Scores of 5 or over are taken to indicate poor health status. (See key above, N=92).

A series of t-tests Table 5.20 were calculated to investigate any differences between the poor health and good health mothers regarding characteristics and social competency of their son / daughter with autism. An example is presented to clarify this.

Are the persons with autism of the "poor psychological health mothers" more aggressive than the persons with autism of the "good psychological health mothers" ?

One tailed t-tests were also calculated to investigate if the "poor psychological health mothers" were experiencing greater levels of family burden and more social problems than the "good psychological health mothers". No significant differences were found between the two health groups in terms of the mother's age ($t = 0.41$; $df = 80$; $p > .05$) or the son or daughter's age ($t = 1.31$; $df = 77$; $p > .05$).

Firstly t-tests were calculated on each section of the A.D.D.C. (Wing, 1987 - Personal Communication) between the two groups of mothers in order to investigate if the persons with autism of the "poor psychological health mothers" had significantly more impairments (as measured by the A.D.D.C.) than the persons with autism of the "good psychological health mothers" (Table 5.19).

Table 5.19: Findings of comparisons between the "poor psychological health" and "good psychological health mothers" on the 3 sections on the A.D.D.C.

		Mean	t value	P
Section A	Group One = 52	12.75	-.60	= .551
	Group Two = 32	13.25		
Section B	Group One = 52	4.27	.38	= .708
	Group Two = 32	4.13		
Section C	Group One = 52	5.81	-.12	= .908
	Group Two = 32	5.88		

A comparison of the 'poor psychological health' (N=32 Group 2) and 'good psychological health' (N=52 Group 1) mothers revealed no differences between the two groups on any section of the A.D.D.C.

The "poor psychological health" mothers were also compared with the "good psychological health" mothers on the measures of family burden. From Table 5.20 it can be seen that significantly greater overall family burden was experienced by the "poor psychological health" mothers ($t = -3.74$; $df = 88$; $p < .0005$).

Table 5.20: The differences between the scores obtained by the "good" and "poor psychological health" mothers of persons with autism on the Family Burden Schedule, the Social Problem Questionnaire, the Vineland Maladaptive Scale and the Index of Social Competence.

Questionnaire	*Number of Cases* §	*Mean*	*t -Value*	*Probability*
Family Burden Schedule	Group One = 56	15.46	-3.74	p = .000 **
	Group Two = 34	23.38		
Social Questionnaire	Group One = 58	3.78	-2.49	p = . 016 *
	Group Two = 34	5.56		
Vineland Maladaptive Scale	Group One = 48	26.25	-2.47	p = .016 *
	Group Two = 28	31.93		
- Vineland Part 1	Group One = 46	20.83	-2.16	p = .034 *
	Group Two = 28	24.93		
- Vineland Part 2	Group One = 47	5.79	-1.63	p = .108 ‡
	Group Two = 28	7.00		
Index of Social Competence	Group One = 40	36.05	-2.06	p = .043 *
	Group Two = 22	40.68		

* - Significant at the .05 Level ** - Significant at the .01 Level ‡ - Not Significant at the .05 Level

§ - Group One: "Good Health Mothers", Group Two: "Poor Health Mothers"

There was a similar pattern of results when a comparison of the mean scores on the social questionnaire was calculated between the "good psychological health" mothers (mean score = 3.78) and "poor psychological health" mothers (mean score = 5.56). The latter group experienced significantly more social problems ($t = -2.49$; $df = 90$; $p < .05$) (See Table 5.21).

Table 5.21 presents the findings of comparisons between the two groups for some individual questions on the Social Questionnaire. These are concerned with problems that may be experienced in the parents' relationship.

Table 5.21: Differences between "Poor Psychological Health" and "Good Psychological Health" Mothers on Social Questionnaire

Items of Social Questionnaire	Z Score	Probability
- 'Difficult confiding in partner'	Z = -7.0	p <.00005
- 'Sexual problems in relationship'	Z = -7.3	p <.00005
- 'Problems getting on together'	Z = -4.66	p <.00005
- 'Satisfaction with relationship'	Z = -4.66	p <.00005
- 'Consideration of separation'	Z = -7.2	p <.00005

For all questions the "poor psychological health" mothers experienced more problems with their partners than mothers considered to be in "good psychological health". This suggests increased stress in the marital area for mothers of "poor psychological health" with an autistic person in the family as compared to mothers with "good psychological health" also with an autistic person in the family.

Differences were also found in relation to their "housing conditions" and their "levels of satisfaction" with it ($t = -2.5$, $p < .05$) with the "poor psychological health" group of mothers with an autistic person scoring lower than the "good psychological health" group of mothers of an autistic person (i.e. "poor psychological health" mothers experienced more problems associated with housing).

Differences between the two groups were also found in the section of the Social Questionnaire addressing (i) relations with their other children in the family, (ii) their ability to cope with them, and (iii) their levels of satisfaction with this relationship. When these three questions were summed the "poor psychological health" group experienced more difficulty with their other children than their counterparts in the "good psychological health" group ($t = -2.1$; $p < .05$).

When comparisons were made between the two groups on the different sections on the Family Burden Schedule some statistical differences were found. The findings, using chi square analysis are reported in the following Table 5.22.

Table 5.22: Family Burden Schedule (Comparison of "Poor Psychological Health" and "Good Psychological Health" mothers)

	Chi Sq.	df	P
- 'Levels of family interaction'	9.7	2	<.01
- 'Family leisure'	8.0	2	<.05
- 'Physical health'	10.78	2	<.005
- 'Mental health'	11.27	2	<.005

There was no statistically significant differences between the 2 groups with regard to the overall financial burden experienced (chi square = 5.1; df = 2; $p > .05$). Also there was no overall statistically significant difference between the "poor psychological health" group and "good psychological health" group on family activities (chi square = 3.5; df = 2; $p > .05$).

Statistical differences between the two groups was almost significant when compared on the overall score on the Vineland Maladaptive Scale ($t=-2.47$, $df=74$; $p<.05$). There was also a significant difference between the two health groups on Part 1 of the Vineland Maladaptiveness Scale ($t=-2.16$; $df=72$; $p<.05$). Part 1 measures less severe forms of maladaptive behaviour. A comparison of the individual questions on Part 1 of the scale also revealed that persons with autism of mothers with "poor psychological health" were more stubborn than persons with autism of the "good psychological health" mothers (chi square = 8.25; df = 2; $p < .05$).

There was no difference between the "poor psychological health" mothers and the "good psychological health" mothers on Part 2 of the scale ($t=-1.65$; $df=73$; $p>.05$). However a more detailed investigation comparing the two health groups on individual questions in Part 2 of the scale revealed that offspring of mothers with "poor psychological health" were found to have more habits / mannerisms (chi square = 7.93; df = 2; $p < .05$).

A comparison of group means on the Index of Social Competence revealed a significant difference between the two health groups ($t=-2.06$; $df=60$; $p<.05$). By looking at the mean scores for both groups on the Index of Social Competence it is evident that offspring with "poor psychological health"(mean score=41) mothers were more dependent than the offspring of the mothers in the "good psychological health group" (mean score=36).

5.16 Level of Impact on Siblings and on the Family

Mothers were also asked if their son or daughter with autism impacted on other siblings in the family and if so the nature of this impact. Five mothers (5%) said that this was not applicable while the remainder indicated the level of impact on a four point rating scale. Over half (57%) of the mothers estimated this impact to be moderately or severely negative. The remainder said that the impact was slight (20%) or that their child's special needs had no impact on his/her siblings (17%).

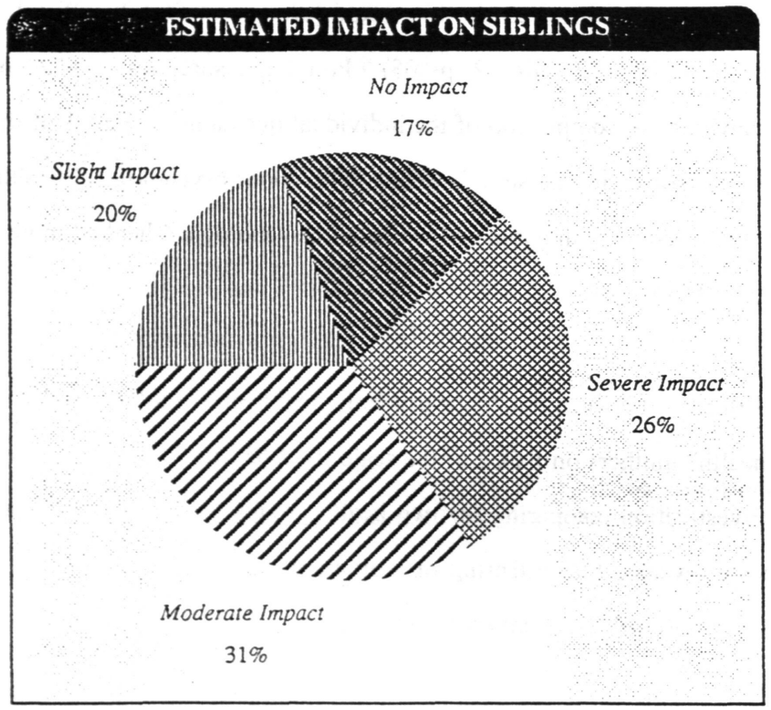

Figure 5.19: The percentages of parents indicating that having a son / daughter with autism had no impact, slight, moderate or severe impact on siblings (N=93).

Sixty eight percent (68%) of mothers stated that their contact with their other children was negatively affected in some way because of the demands made by the child with special needs, 18% said that it was severely prohibited, 33% felt it was moderately prohibited while 17% said it was slightly prohibited. Only 7% said that having a child with special needs improved their relationship with their other children and 22% said it

did not prohibit the amount or quality of contact they had with their children. The remainder did not respond to this question.

Sixty two per cent of the mothers said that their other children helped to care for their brother or sister with autism, while 32 (35%) were not involved in the care of their sibling. The remaining 3% helped a little but not much. When asked to describe the nature of their involvement eight mothers said that other children were too young to help with their sibling with autism and another three mothers said that it was not suitable to have them involved. A number of mothers (N=14) reported that they did not want to burden their other children with the care of their child with autism. One mother reported that her other children could not cope with their sibling with autism.

The nature of the help provided by those who did help care for their sibling with autism included general help (N=33), taking their sibling out (N=12), playing with their sibling and making a meal (N=1).

Only 28% of mothers felt that their son or daughter with autism was not overprotected, while 2% of the mothers were not sure if their child was overprotected. The remainder felt that their child with autism was overprotected either severely (N=11,12%), moderately (N=39, 41%) or slightly (N=16,17%).

When asked if the siblings of their child with autism were concerned about the genetic aspects of autism the majority of mothers replied that they were not concerned (N=30, 30%) or else mothers did not know (N=26, 27%). A further thirteen mothers (14%) said that this question was not applicable at that time. However some siblings were concerned about the genetic aspects of autism, this concern ranged from severe worry (N=8, 8%), to moderate worry (N=12, 13%) to slight worry (N=7, 7%).

Mothers were asked about their caring experiences. The findings are outlined in Table 5.24. Just over half of the mothers (52%) were always or often emotionally drained from

caring. Few (4%) were never emotionally drained from caring for their person with autism. Again over half of the mothers (53%) felt used up at the end of the day after caring for their person with autism. Many mothers (43%) often or always felt fatigued in the morning and could not face the day. A similar number of mothers (43%) considered themselves to be often or always burned out from caring and only five mothers said that they were never burned out from caring. Half of the mothers (50%) also felt frustrated from caring for their person with autism. Approximately one half of the mothers (46%) felt energetic when it came to caring for their person with autism. Finally not everyone (N=21) felt it was a worthwhile, rewarding experience caring for their person with special needs. Nineteen mothers occasionally felt it was rewarding while the remaining mothers (N=48) felt that it was often or always a rewarding experience caring for their person with autism.

Table 5.23: Feeling of mothers with regard to caring for their person with autism.

	Never N (%)	Seldom N (%)	Occasionally N (%)	Often N (%)	Always N(%)
Emotionally drained from caring?	4 (4%)	12 (13%)	29 (31%)	22 (24%)	26 (28%)
Feel used up at the end of the day	6 (6%)	11 (12%)	27 (29%)	25 (27%)	24 (26%)
Feel fatigued to get up in the morning and face the day ?	6 (6%)	15 (16%)	31 (34%)	22 (24%)	18 (20%)
Feel burned out from caring?	5 (5%)	11 (12%)	37 (40%)	18 (20%)	21 (23%)
Feel frustrated from caring?	7 (8%)	9 (10%)	30 (33%)	28 (30%)	18 (19%)
Feel very energetic?	5 (5%)	11 (12%)	42 (46%)	23 (25%)	11 (12%)
Feel that it is a worthwhile experience caring for child?	11 (12%)	10 (11%)	19 (22%)	26 (30%)	22 (25%)

5.17 Findings from the Control Group

As described in the method section a control group comprised of mothers (N=30) of children in the normal school system were also interviewed. 24 mothers were married/cohabiting, five were single and one mother was widowed.

The findings are as follows:

Vineland Maladaptive Behaviour scale

The majority of children in the control group did not exhibit many maladaptive behaviours, for example, one child sometimes sucked his/her thumb and another child always did so, four children sometimes bit their nails and another three children always did so. Scores for the children in the control group are presented in the following table (Table 5.24).

As described in the method section mothers were asked to indicate whether their child displayed any maladaptive behaviours, the responses were 'no', 'sometimes' and 'yes-usually'. Only the numbers of children in the control group who 'sometimes' or 'yes-usually' displayed minor maladaptive behaviours are displayed.

Table 5.24: The scores for the Vineland Maladaptive Domain - Part 1 for children in the control group.

	Sometimes	Yes Usually
Sucks thumb or fingers	1 (3%)	1 (3%)
Is overly dependent	2 (7%)	-
Withdraws	8 (27%)	1 (3%)
Wets bed	5 (17%)	-
Exhibits an eating disturbance	-	-
Exhibits a sleep disturbance	-	-

Bites fingernails	4 (13%)	3 (10%)
Avoids school or work	2 (7%)	-
Exhibits extreme anxiety	3 (10%)	-
Exhibits tics	-	-
Cries or laughs to easily	5 (17%)	-
Has poor eye contact	-	-
Exhibits excessive unhappiness	1 (3%)	-
Grinds teeth during day or night	3 (10%)	-
Is too impulsive	9 (30%)	1 (3%)
Has poor concentration or attention	8 (27%)	-
Is overly active	-	-
Has temper tantrums	5 (17%)	3 (10%)
Is negativistic or defiant	4 (13%)	2 (7%)
Teases or bullies	11 (37%)	2 (7%)
Shows lack of consideration	3 (10%)	2 (7%)
Lies, cheats or steals	8 (27%)	-
Is too physically aggressive	1 (3%)	1 (3%)
Swears in inappropriate situations	5 (17%)	2 (7%)
Runs away	1 (3%)	-
Is stubborn or sullen	11 (37%)	-
Is truant from school or work	-	-

As expected school-age children did display some minor maladaptive behaviours, eleven children were described by their mothers as sometimes being stubborn or sullen.

None of the children in the control groups exhibited an eating or sleeping disturbance or any tics.

Only two children in the control group were physically aggressive, one usually and one only sometimes.

Almost a quarter of children in the control group (N=7, 24%) displayed inappropriate social behaviour by swearing in the wrong situation. Only one child in the control group tried to run away yet based on the mother's report.

Very few of the control children displayed any of the major maladaptive behaviours investigated on part 2 of the Vineland Maladaptive Behaviour Scale. Two children, according to their mothers sometimes were preoccupied with an object. One child in the control group sometimes displayed self-injurious behaviour. Two mothers reported that their children destroy property all the time while another child only sometimes engaged in this behaviour.

Comparison of the two groups using a t-test was not calculated due to the very small number of children in the control group displaying any of the major maladaptive behaviour (mean score = 0.233 behaviours).

The findings relating to the Index of Social Competence are presented in the next section.

Index of Social Competence

As one would expect all the children in the control group had normal hearing and normal vision. No children in the control group had a history of epilepsy. The majority of children in the control group (N=28, 93%) could remember and carry out a sequence of instructions. Only one child in the control group lacked clarity of speech.

All children in the control group were able to feed themselves according to their mothers. All of the children in the control group were independent with regard to looking after their personal needs and all were completely mobile. In the control group all of the children except two were fully competent in the use of their hands.

In the control group twelve persons (40%) could prepare all meals and a further nine (30%) could prepare simple hot foods. Five children (7%) in the control group needed all

foods prepared for them, the remaining 7 children (23%) could prepare foods for themselves that did not require any cooking.

The majority of children in the control group could read and follow a series of written instructions (N=24, 80%). Almost all of the children in the control group were able to write (N=26, 87%), 3 children (10%) could write their own name and address without help and the remaining child (3%) could write their name.

Twenty six (87%) of persons in the control group could time activities and understand time. In keeping with the other findings the majority of children in the control group could use money responsibly (N=27, 90%), two children (7%) could select the amount of money appropriate to the stated price of an article.

Family Burden Questionnaire

On the Family Burden Questionnaire mothers in the control group reported much less burdens. One mother reported that her child's disruption of family interaction had led to a general ill atmosphere in the house. The same mother reported that there had been an adverse effect on her health due to her child's behaviour, and she rated this burden as moderate.

Another mother in the control group reported that her child disrupted the activities of other members of the family (as they had to look after the child) or else the child stopped normal recreational activities, and these were rated as moderately inconvenient. The same mother also reported that there was on ill effect on the general atmosphere in the house, and this caused moderate burden to the family according to the mother. This mother also stated hat her child's behaviour had discouraged relatives and neighbours to visit and this was a moderate burden. Finally this same mother reported that other family

members had suffered physical ill health due to the child's behaviour and this was also a moderate burden.

The remaining 28 mothers did not report any problems on the family burden questionnaire. Since the number of mothers who reported family burdens relating to their child was so low it was decided not to conduct statistical significance tests comparing the mothers in the control group with the mothers of children with autism.

Social Problems Questionnaire

As was the case with the Family Burden Questionnaire few mothers in the control group reported social problems. Those who did report social problems are discussed individually. One mother reported that her housing conditions were slightly inadequate and she had difficulty getting on with close relatives. Another mother similarly reported that she was not satisfied with her accommodation, she had severe financial difficulties and she reported that she did not get out enough. Another mother also said that she was markedly dissatisfied with the amount of time she had to go out.

Seven mothers reported minor financial difficulties (one mother reported marked difficulties with their financial position) and four mothers reported some difficulties meeting bills. While an additional two mothers reported marked difficulty regarding the adequacy of the money coming in to meet the family's needs. One mother reported that her housing conditions were slightly inadequate while another mother reported that her housing conditions were markedly inadequate. Finally one mother reported that she was slightly dissatisfied and another that she was markedly dissatisfied with their present accommodation.

As was the case with the Family Burden Questionnaire it was decided not to statistically compare the two groups (autism versus control) since so few social problems were identified by the mothers in the control group.

General Health Questionnaire

In the following table (Table 5.25) the mean scores and standard deviations obtained by mothers of persons with autism and control subjects on the General Health Questionnaire (GHQ) are presented.

Table 5.25: Mean score and standard deviation (SD) on the GHQ for Mothers of Persons with Autism and Mothers of persons in the control group attending the normal schools.

Group	Mean	SD
Group with Autism	5.10	6.5
Control Group	3.03	5.3

The maximum score achieved was 18 for the control group and 26 for mothers of persons with autism. Comparison of the mean scores revealed no significant difference between the two groups on the GHQ. This finding may be due to the fact that in the control group one mother scored 18 and another scored 15 even though the majority of the group scored below 5 (N=24, 80%), the cut-off score. The outliners in the control group may have led to an elevated mean score for that group.

The following Table 5.26 outlines scores achieved by the two groups for the individual items on the GHQ. There were very marked differences between responses of mothers of persons with autism and control mothers on individual items of the GHQ.

Table 5.26: Scores for the Individual Items on the GHQ for Mothers of Persons with Autism and Mothers of Persons in the Control Group attending the Normal Schools.

	Mothers of persons with autism		Mothers of control subjects	
	Score 0	Score 1[4]	Score 0	Score 1
1. been able to concentrate on whatever you're doing	74%	26%	83%	17%
2. lost much sleep over worry?	76%	24%	83%	17%
3. been having restless, disturbed nights?	71%	29%	87%	13%
4. been managing to keep yourself busy and occupied?	92%	8%	100%	0%
5. been getting out of the house as much as usual?	78%	22%	90%	10%
6. been managing as well as most people would in your shoes?	91%	9%	93%	7%
7. been feeling on the whole you were doing things well?	88%	12%	93%	7%
8. been satisfied with the way you've carried out your task?	84%	16%	93%	7%
9. been able to feel warmth and affection for those near to you?	94%	6%	97%	3%
10. been finding it easy to get on with other people?	87%	13%	97%	3%
11. spent much time chatting with people?	87%	13%	73%	27%
12. felt that you are playing a useful part in things?	92%	8%	97%	3%

[4] A score of 0 indicates that the respondent is experiencing problems 'less than usual' or the 'same as usual'. A score of 1 indicates that the respondents is experiencing problems 'rather more' or 'much more than usual'.

	Mothers of persons with autism		Mothers of control subjects	
	Score 0	Score 1	Score 0	Score 1
13. felt capable of making decisions about things?	84%	16%	100%	0%
14. felt constantly under strain?	57%	43%	80%	20%
15. felt that you couldn't overcome your difficulties?	81%	19%	87%	13%
16. been finding life a struggle all the time?	75%	25%	93%	7%
17. been able to enjoy your normal day-to-day activities?	80%	20%	90%	10%
18. been taking things hard?	70%	30%	80%	20%
19. been getting scared or panicky for no good reason?	78%	22%	90%	10%
20. been able to face up to your problems?	91%	19%	93%	7%
21. found everything getting on top of you?	71%	29%	77%	23%
22. been feeling unhappy and depressed?	80%	20%	80%	20%
23. been losing confidence in yourself?	81%	19%	93%	7%
24. been thinking of yourself as worthless person?	92%	8%	93%	7%
25. felt that life is entirely hopeless?	93%	7%	93%	7%
26. been feeling hopeful about your own future?	83%	17%	97%	3%
27. been feeling reasonably happy all things considered?	88%	12%	93%	7%
28. been feeling nervous and strung-up all the time?	81%	19%	83%	17%

	Mothers of persons with autism		Mothers of control subjects	
	Score 0	Score 1	Score 0	Score 1
29. felt that life isn't worth living?	93%	7%	97%	3%
30. found at times you couldn't do anything because your nerves were too bad?	89%	11%	90%	10%

As can be seen from the above Table 5.26 there were differences between mothers in the control group and mothers of persons with autism regarding their health although the two groups did not differ on overall scores for the GHQ. In addition the age of the mothers was not an important factor influencing scores on the G.H.Q. (P=0.6) and neither was the sex of son or daughter (P=0.9).

5.18 Findings from the Qualitative Interviews with the Mothers

While mothers were being interviewed they were asked additional questions regarding their son / daughter with autism (see Appendix C). Questions were related to the type of diagnosis they received about their son / daughter, the problems experienced at different stages of their offsprings development and their immediate plans and future plans for their son / daughter. The findings are outlined in the following section.

Mothers were asked if they had ever received a diagnosis explaining their son or daughter's special needs. There was a variety of answers (N=91). Over a quarter of those interviewed mentioned "autistic tendencies" (26%). Eight mothers (9%) received no diagnosis. Quite a few mothers (N=16, 18%) were told that their offspring was "mentally handicapped and autistic". Seven mothers (8%) were specifically told that their offspring was a "Down's Syndrome child". Eleven mothers (12%) were told that their offspring had "brain damage". Two mothers (2%) were told that their offspring was "mentally handicapped, autistic and deaf", while three mothers (3%) were told that their offspring were "deaf". One mother was told that her offspring was "autistic with a language disorder". Other diagnoses are outlined in the following Table 5.27.

Table 5.27: Diagnosis received by the mother regarding their persons with autism (N=91).

Diagnosis Received by Mothers	N	Valid %
"No diagnosis received"	8	9%
"Autistic tendencies"	24	26%
"Mentally handicapped and autistic"	16	18%
"Down's syndrome"	7	8%
"Brain damage"	11	12%
"Mentally handicapped, autistic and deaf"	2	2%
"Deaf"	3	3%
"Autistic & language disorder"	1	1%
"Slow"	5	6%
"Emotionally disturbed"	4	4%
"Language disorder"	3	3%
"Behavioural disorder"	3	3%
"Epilepsy"	2	2%
"Personality disorder"	1	1%
"Due to mother's contact with rubella"	1	1%

A few mothers were told that their offspring was "slow" (N=5, 6%) and four mothers (4%) had a diagnosis of "emotionally disturbed" for their offspring with autism. A total of three mothers (3%) were given a diagnosis of "language disturbance" while another three mothers (3%) were given a diagnosis of "behavioural disorder".

The distribution of ages of the persons with autism at which any diagnosis was received by parents is shown in Figure 5.20. Information was available for 93 persons with autism. The average age when a diagnosis was made was 4 years (sd=4). Only a minority were made after ten years of age.

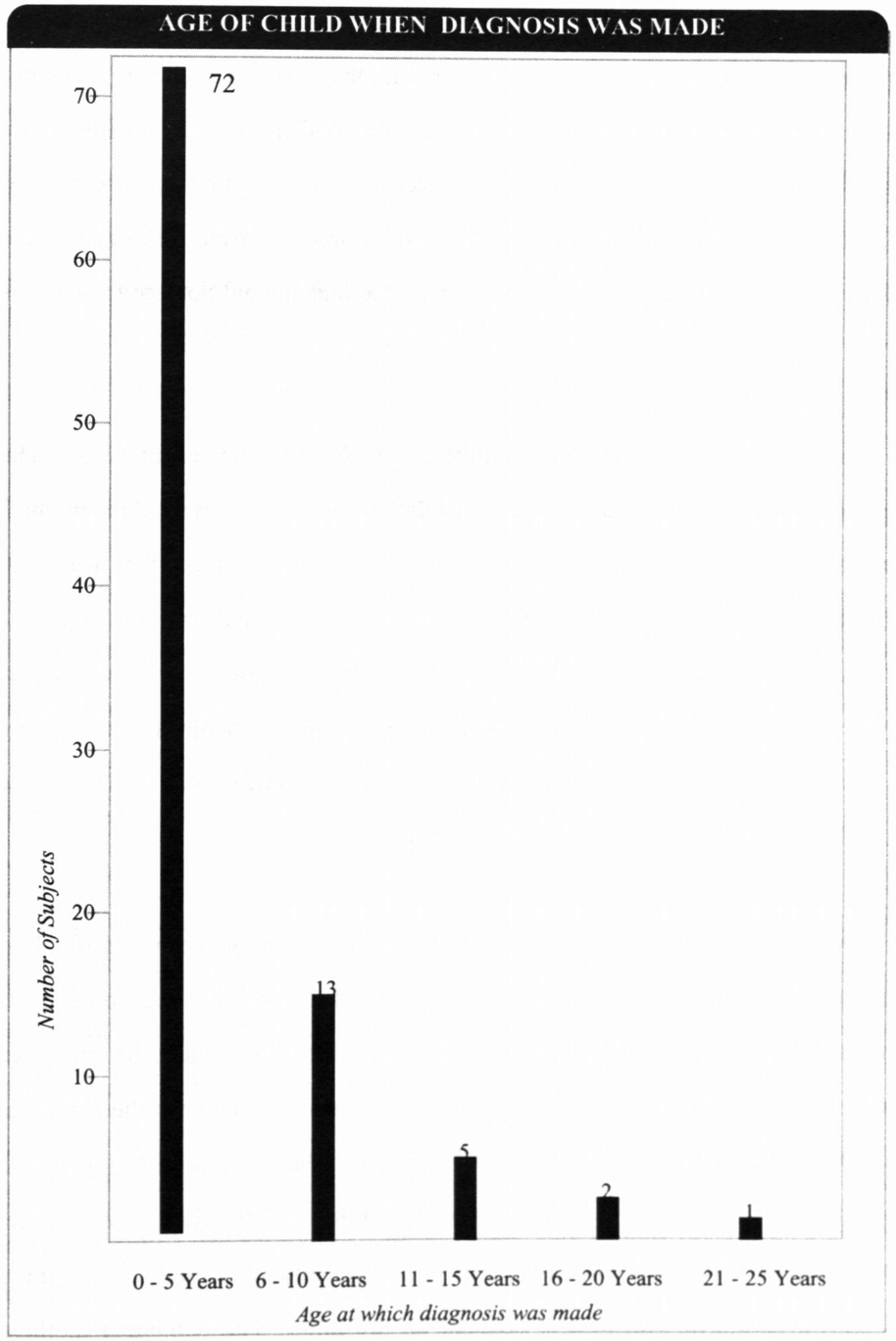

Figure 5.20: Age at which persons with autism were diagnosed according to the mothers.

Mothers were asked about their feelings regarding the diagnoses they received. Thirty two (32) were very upset/shocked. Eleven mothers said that they were relieved to receive a diagnosis. One mother felt guilty and a further eleven mothers reported that they were very frustrated. Eleven mothers said that they agreed with the diagnosis and were happy to get it. However eight mothers said that they still wanted an exact diagnosis. One mother who was told that her child was autistic reported that she did not know what this meant.

Mothers were then asked how they felt about the diagnosis at the time of interview. The following mothers (N=34) said that they accepted things and were relieved; three mothers still described themselves as feeling guilty and five mothers reported that they were still shocked with the autistic diagnosis. A further five mothers reported that they still have not fully accepted the situation. Two mothers reported that they tried not to worry about things. One mother said that she was pleased that her child was diagnosed at a young age, yet four mothers reported that they still did not know much about autism. One mother said that she disagreed with the diagnosis she received.

Mothers were asked to identify the times in their child's life they found it most difficult to cope with their child's disability. Four mothers reported that their child was not difficult to cope with. Thirty three of mothers (N=33, 33%) reported it was when the child was very young, before they started school. Thirteen mothers said it was when the child was starting school and 15 mothers said it was during primary school age years (up to age 11 years). A number of mothers (N=14) said it was around the time of puberty/adolescence. One mother said that she found it most difficult when her child left school. Six mothers said that their person with autism was difficult all the time. The remaining mothers (N=14) said it was getting more difficult as their offspring grew older (late teens/twenties).

5.19 Further Aspects of Services for Persons with Autism

The results concerning the services utilised by persons with autism and their families are reported - the frequency of their use among individuals, levels of satisfaction with services, and the utilisation of residential and community facilities. The findings relating to the regularity with which psychiatric, psychological, paediatric, physiotherapeutic, social work, speech therapy and other services are utilised by persons with autism and their families are presented. Results concerning specific training received by staff are also presented. All of the above information was obtained by interviewing the key workers in the different centres providing services to persons with autism.

Key workers were asked if the client(s) in their centre had a written individual educational plan specifying strengths/weaknesses, their special learning needs and learning goals; 224 of the 272 persons (82%) with autism identified in this study did have such a plan. However 41 persons with autism did not. This information was missing for five individuals and in the case of two persons with autism the staff member interviewed did not know if they had an individual educational programme plan (IEP). Key workers were also asked to indicate if the parents were involved in the formulation and review of the client's IEP. Staff indicated that 152 parents (56%) had no involvement in their child's IEP; 112 parents (41%) were involved and two key workers did not know if parents were involved.

Some staff specified the nature of the parent's involvement (N=110). The majority of parents attended meetings (N=97, 88%), while nine parents (8%) helped decide on the needs and programme goals of their child.

There was information available for 217 persons with autism regarding the regularity with which their IEP was reviewed (see Figure 5.21). The majority (N=91, 42%) had their IEP reviewed twice a year or yearly (N=57, 26%). Quite a large proportion had their IEP

reviewed every two or three months (N=45, 21%). Only a small minority had their educational plans reviewed monthly (N=8, 4%) or every few weeks (N=16, 7%).

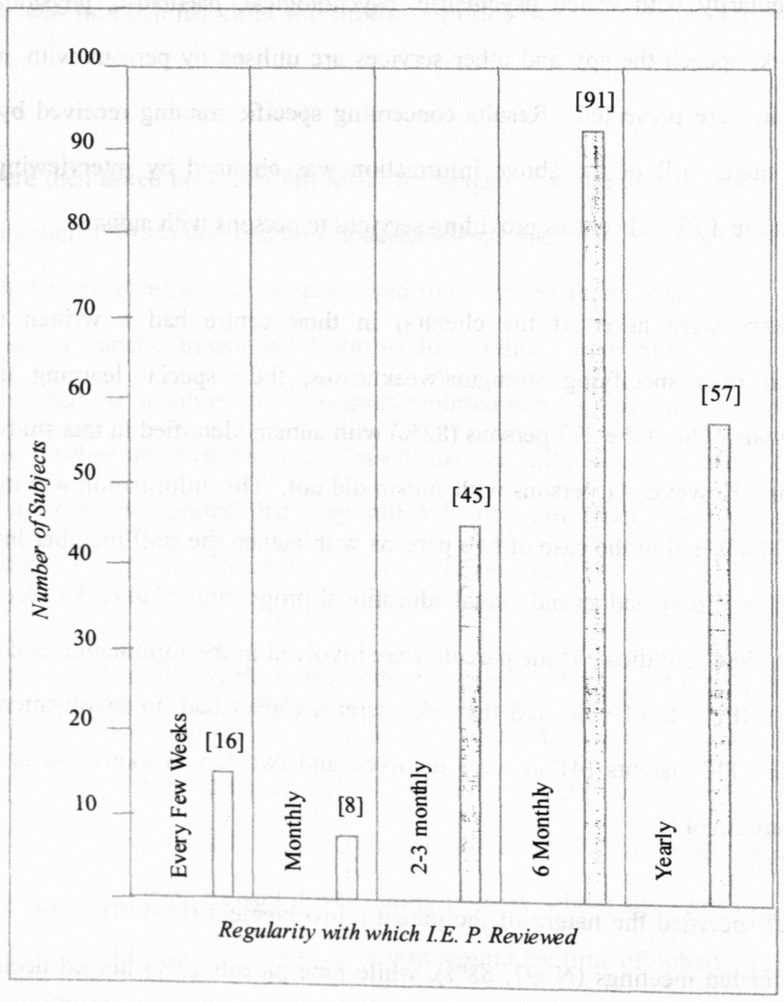

Figure 5.21: The frequencies with which Individual Education Plans are reviewed (N=217).

The level of contact reported as occurring between staff and parents is indicated in Figure 5.22 below. Only a very small minority of parents had contact with staff on a daily basis (N=2) or a weekly basis (N=5). A large proportion of parents met staff only when they felt it was needed (N=44). However a considerable number of parents met with staff monthly (N=75), or every six months (N=63) or else once a year (N=41). A small number of parents (N=6) had no direct involvement with staff.

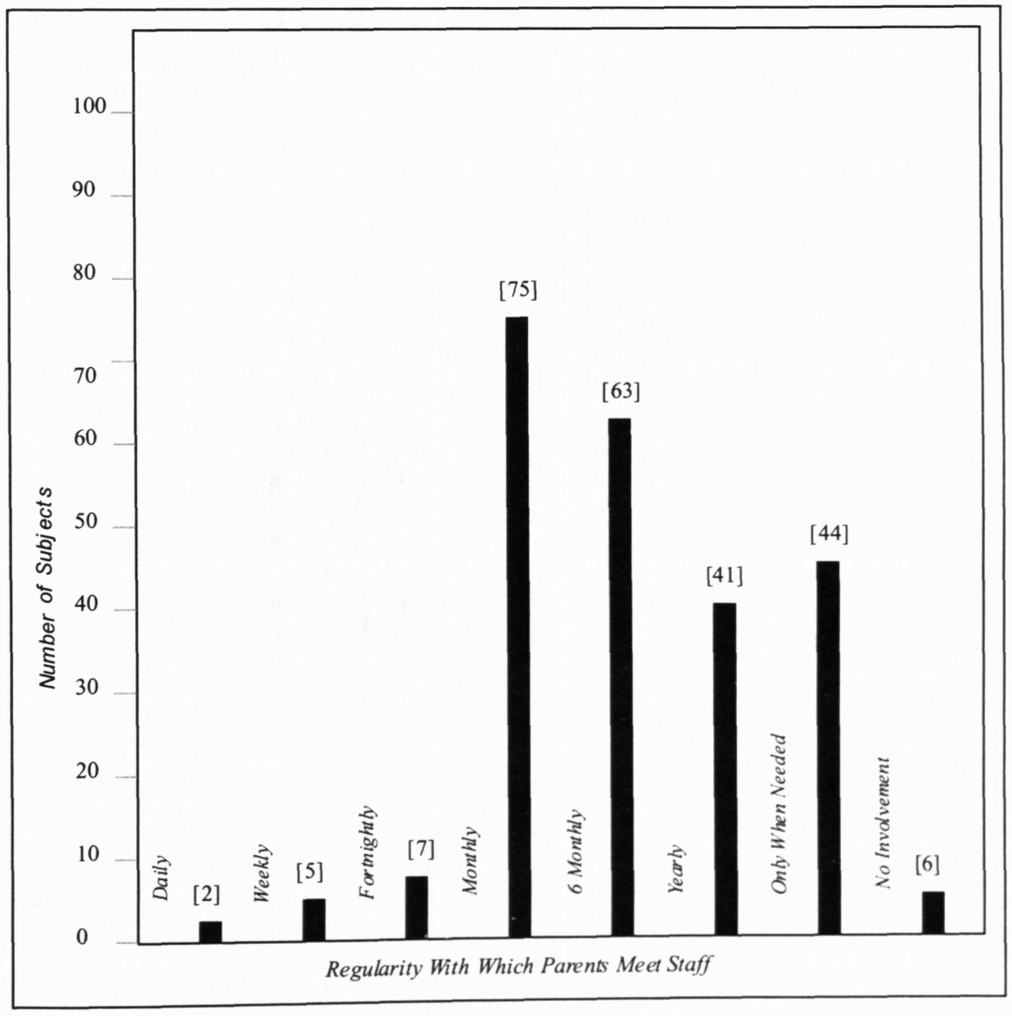

Figure 5.22: The regularity with which parents of persons with autism meet staff (N=243).

Four per cent of persons with autism (N=10) received their IEP alone without any other person with special needs being present. The number of persons with special needs being present when an IEP was being delivered ranged from zero to 42 others. It can be seen from the figure below that the majority of persons with autism received their IEPs in a group of 4 or more.

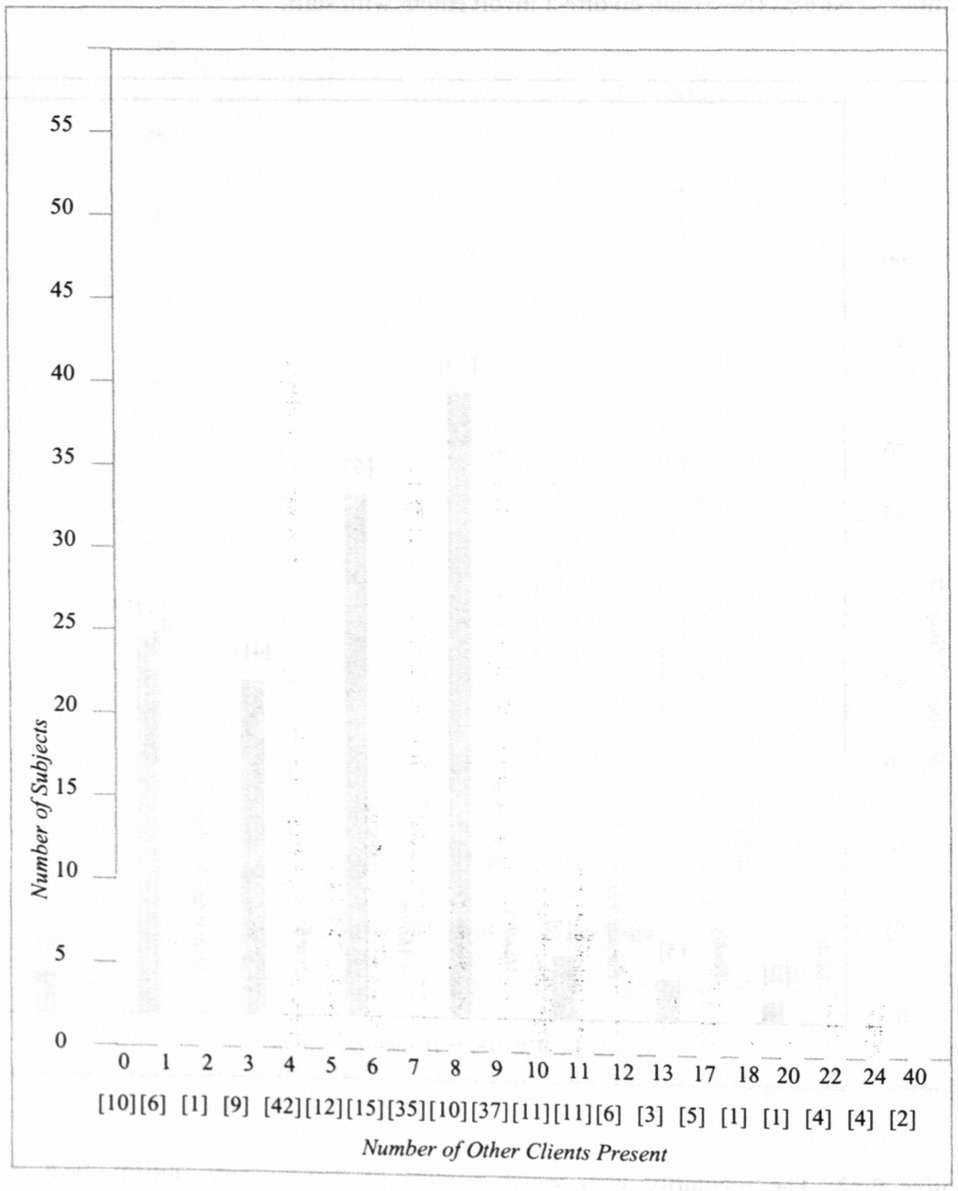

Figure 5.23: The numbers of other persons present when the subjects' Individual Education Plans were being delivered (N=225).

The reported average ratios of staff to clients in services attended by persons with autism is presented in Figure 5.24.

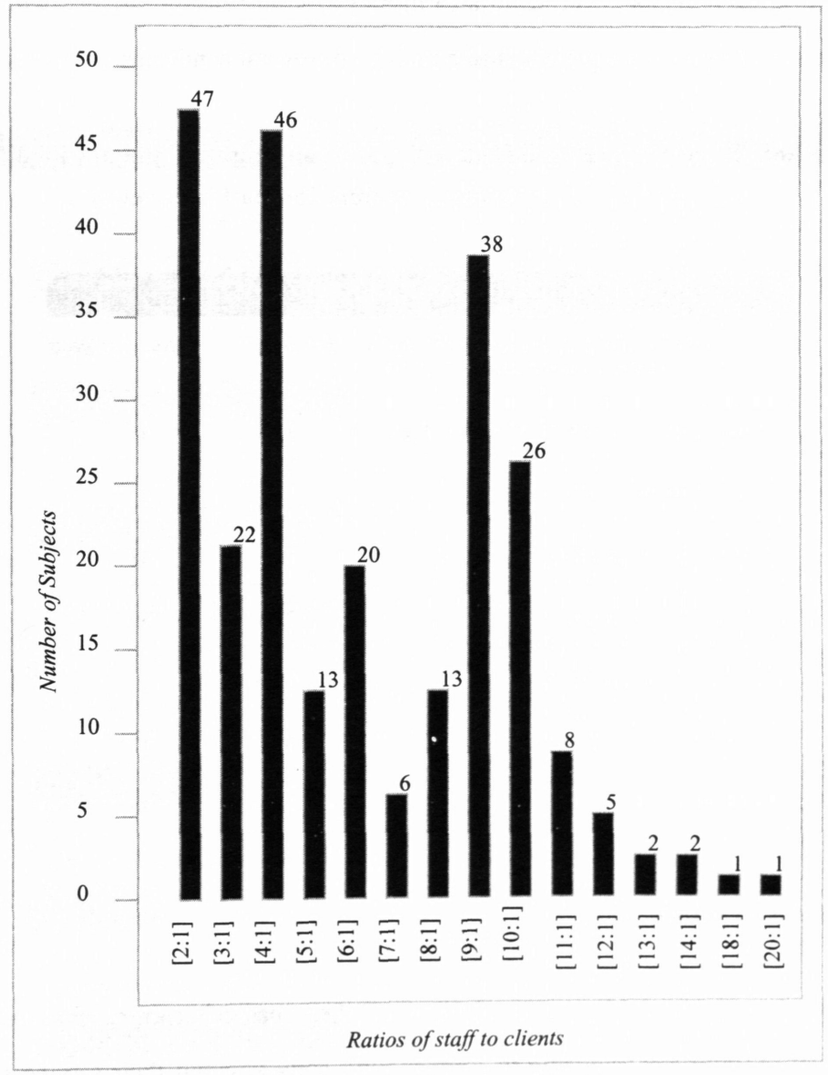

Figure 5.24: The numbers of persons with autism having staff-client ratios of between 2:1 and 20:1. (N = 252)

5.20 Sharing Classrooms with Non-autistic Persons

The following Table 5.28 shows the percentages of subjects with autism and the persons they shared a classroom with. This comprised of individuals of normal intelligence, and

those possessing a mild, moderate, severe or profound mental handicap in key workers judgement which would be based on all the data available in the case notes on each individual in each centre. The table also displays the number of persons with autism sharing classrooms with people who had a mixture of several handicaps.

Table 5.28: The percentages of persons with autism sharing a classroom with different groups (information was available from 264 staff interviews)[3] .

WITH WHOM SHARE CLASSROOM?		
Level of Ability of Individuals with whom Subjects with Autism Share Classroom	*Percentage*	*No. of Subjects*
Normal Intelligence and Additional Handicap	17%	45
Mild Mental Handicap	3%	8
Moderate Mental Handicap	18%	48
Severe Mental Handicap	22%	59
Profound Mental Handicap	0.5%	1
Autism and Related Handicaps	6%	17
Mixed Handicaps	33%	86

5.21 Skills Training

The following figure 5.25 is a breakdown of the areas of learning focused on in educational programmes available to persons with autism within their service settings. As can be seen from the figure a considerable number of persons with autism were engaged in learning independent living skills (40%), music therapy (41%) and language

[3] Normal intelligence and additional handicaps would include emotional and behaviourally disordered children (Commission of EC (1992) Sec (92) 1891 Final).

Category of mixed handicaps would be multiply handicapped as identified in The Report of the Commission of the Progress with regard to the implementation of the Policy of School Integration. Mixed and additional handicaps would include physical, hearing, visual or language (Commission of European Communities (1992) Sec (92) 1891 Final). These handicaps were based on the subjective judgements of the staff of the centres. Precise identification of handicaps would require psychometric assessment and detailed physical examination which was beyond the scope and resource of this study.

skills training (35%). Thirty-eight per cent received play therapy and 35% were involved in cognitive skills training. Much smaller numbers were engaged in relationship skills training (18%) or recreational skills training (16%). Self help social skills training and swimming were availed of by 6% and 7.5% of persons with autism respectively.

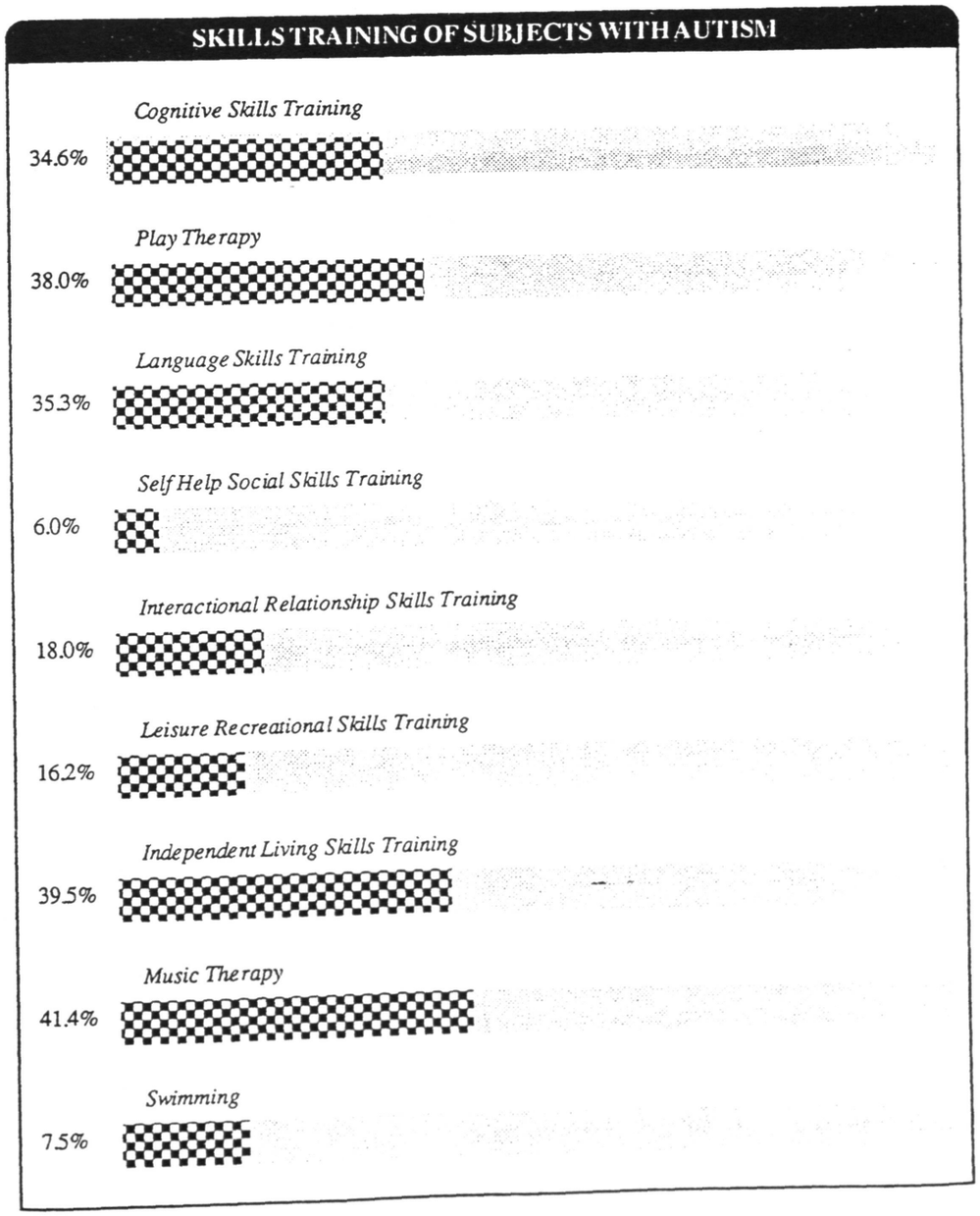

Figure 5.25: The percentages of persons with autism receiving specific training in the named areas.

Many persons with autism (N=161, 61%) also had leisure and recreational skills in their IEP (Individual Educational Plans). Also the majority of persons with autism (N=223, 84%) had a physical education regime as part of their IEP. A small number (N=47, 18%) had horse riding included in their IEP. Also quite a large number of persons (N=159, 60%) with autism were being trained to use community facilities, shops and restaurants.

Staff were also asked to specify the amount to time clients were involved in their IEP. Information was available for 158 persons with autism. Some persons with autism were involved in their IEPs for one hour on a daily basis (N=29, 18%). Four people (3%) had less than one hour involvement in their IEP while 17 people (11%) had two - three hours a day spent working on their IEP. The rest were as follows; four hours (N=3, 2%), five hours (N=36, 23%); six hours (N=49, 31%); ten hours (N=18, 11%).

5.22 Access to Professionals

Staff were also asked to indicate how often persons with autism attended professional services. A small number (n=8, 3%) did attend a physiotherapist on a daily basis according to the key members of staff interviewed although the majority of clients received physiotherapy when required (N=164, 61%). In fact for a lot of persons with autism this service was not applicable (N=92, 34%). The remainder had physiotherapy weekly (N=2, 0.7%) or once a year (N=1, 0.4%) (Figure 5.26). For the majority speech therapy services (Figure 5.27) according to the key workers were not applicable (N=106, 40%). The following proportion received speech therapy when required (N=95, 36%). The number who had speech therapy daily was 41 (15%). The remainder received this service on a weekly, monthly or fortnightly basis (N=13, 5%). Ten people (4%) attended a speech therapist twice a year. The majority of persons with autism attended a psychologist when required (N=224, 84%) (Figure 5.28).

The need to see a psychologist was reported by the key workers to be non-applicable to a small number (N=19, 7%). The remainder had contact with a psychologist twice a year (N=13, 5%) or yearly (N=3, 1%). Again social work services were mainly used when required (N=184, 69%) and for a large proportion it was regarded as not applicable (N=48, 18%) (Figure 5.29). Only a small number had contact with a social worker on a daily basis (N=18, 7%). Twelve persons with autism (4.5%) had contact twice a year and one (0.5%) had yearly contact with a social worker. Only two persons with autism (1%) received paediatric services regularly or every two weeks (Figure 5.30). As would be expected, for many people paediatric services not applicable (N=51, 19%) or was available only when required (N=173, 65%). The remainder had yearly (N=38, 14%) or twice yearly (N=3, 1%) contact with a paediatrician. There was no major change in access to professional services when it came to receipt of psychiatric services (Figure 5.31). Again for the majority psychiatric services were availed of when required (N=198, 74%) or else this service was not applicable (N=55, 20%). Only two persons with autism (1%) saw a psychiatrist daily. A further 7 persons had weekly contact (N=7, 3%) or contact once every two weeks (N=2, 1%) with a psychiatrist. The remaining 3 people (1%) saw a psychiatrist twice a year.

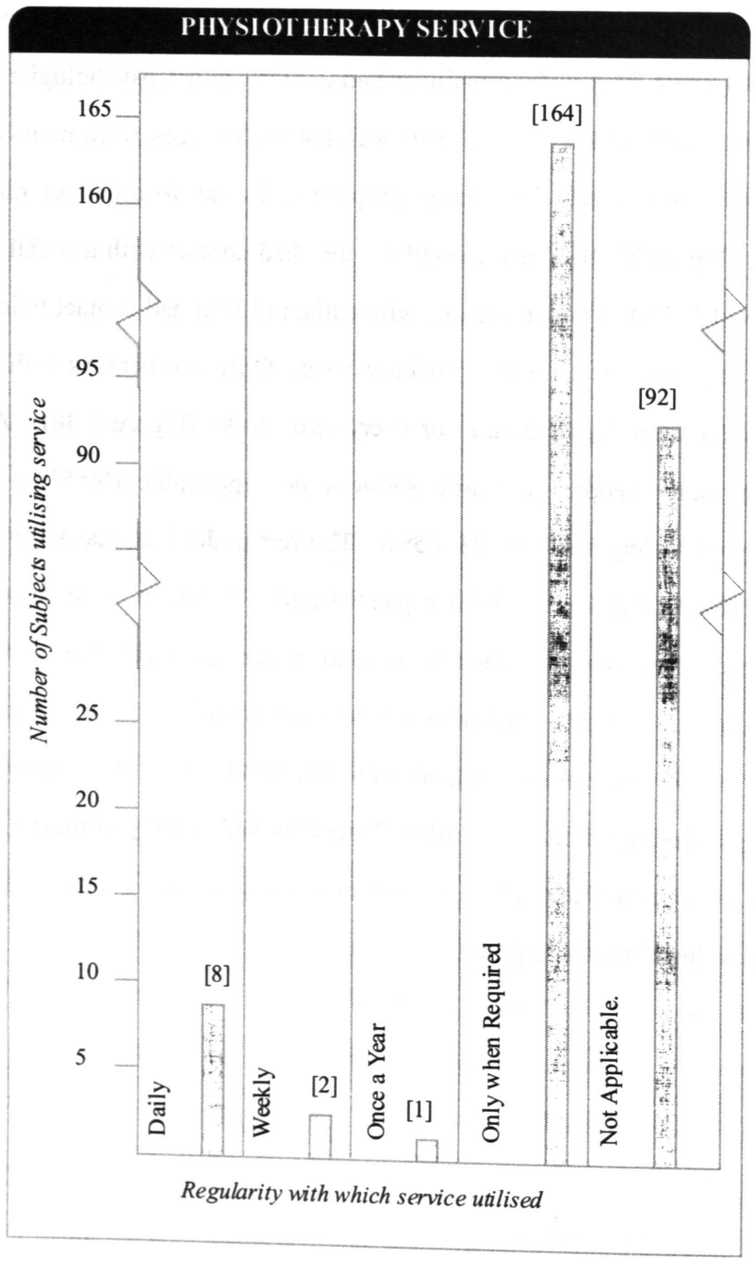

Figure 5.26: The frequency with which subjects utilised physiotherapy services (N=267).

There was a somewhat similar pattern regarding access to speech therapy services and access to physiotherapy for persons with autism with the majority attending every six months or when necessary.

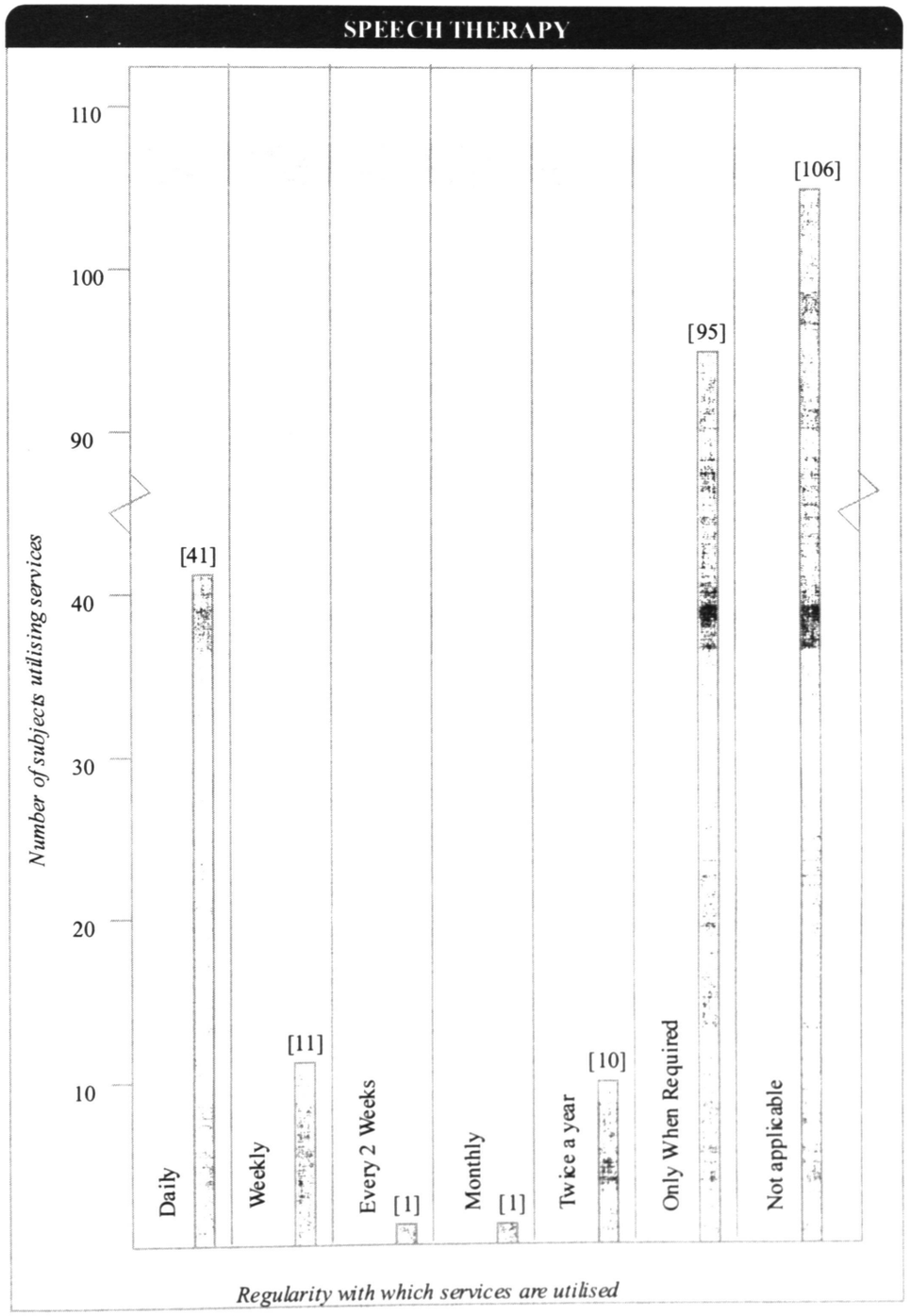

Figure 5.27: The frequency with which subjects utilised speech therapy services (N=265).

Similarly with access to psychological service the majority of persons with autism attended when necessary.

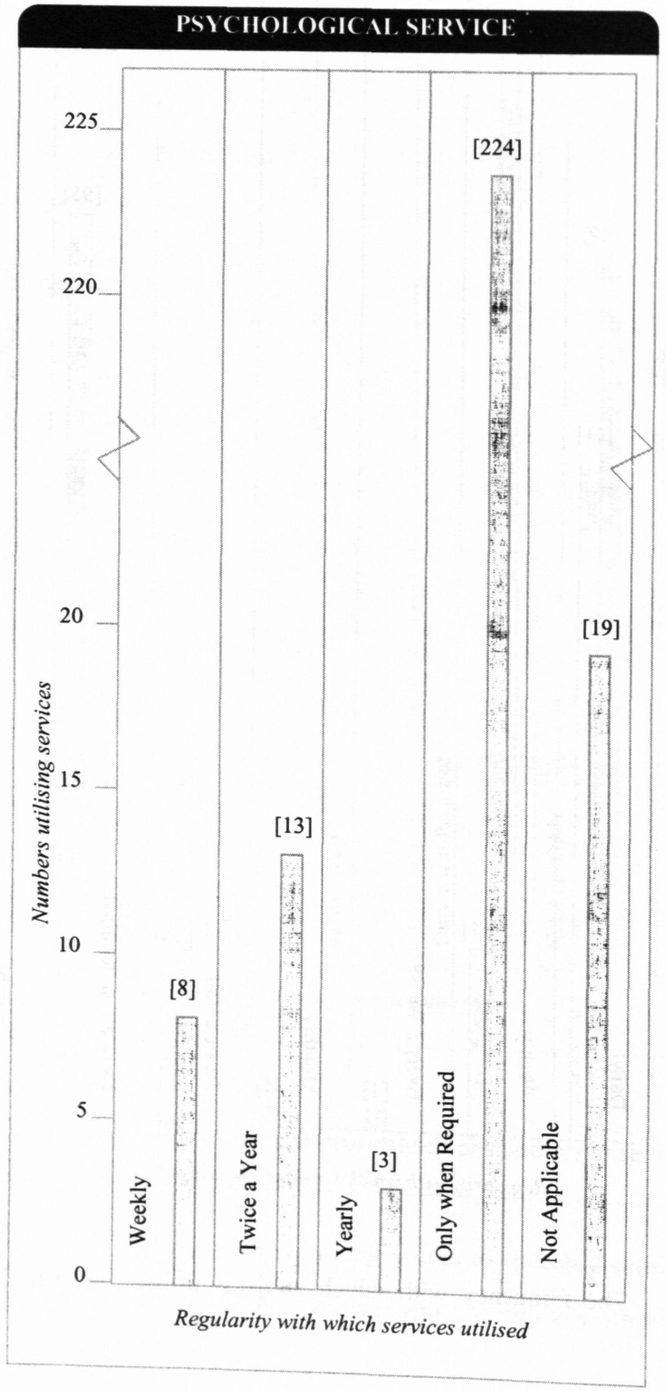

Figure 5.28: The frequency with which subjects utilised psychological services (N=267).

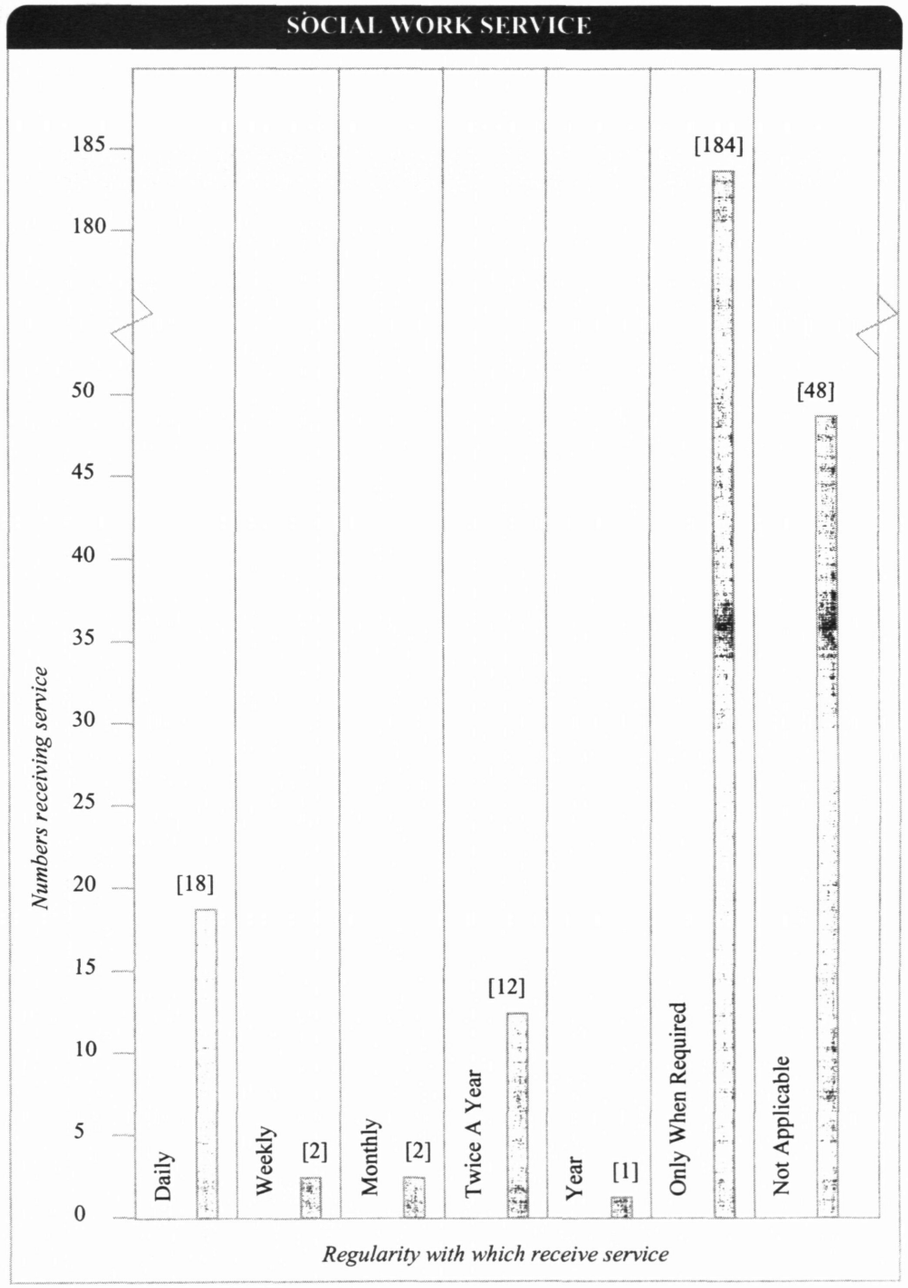

Figure 5.29: The frequency with which subjects utilised social work services (N=267).

A small proportion of persons with autism received social work services on a daily basis (N=18). Again the majority of persons received these services when required.

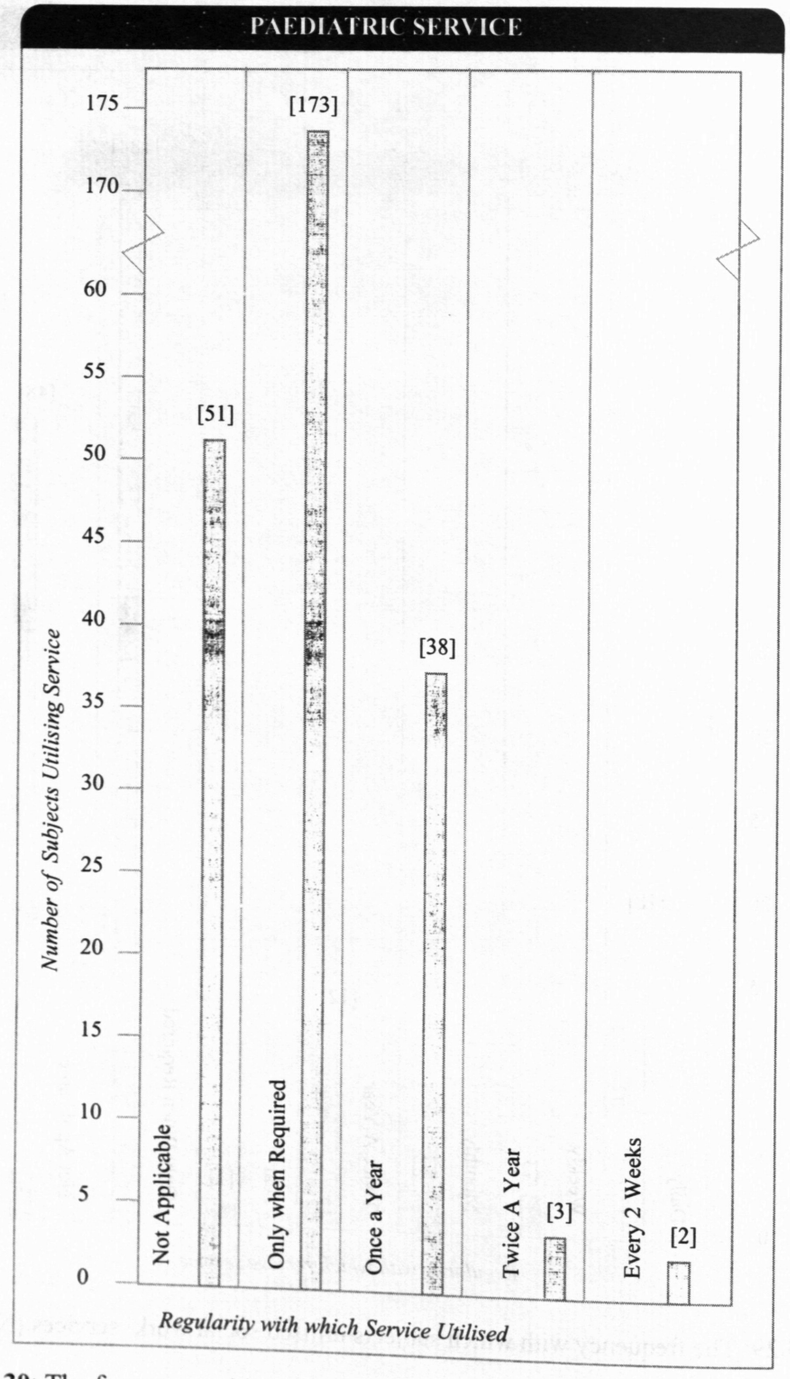

Figure 5.30: The frequency with which subjects utilised paediatric services (N=267).

Only two persons with autism were in receipt of paediatric services every two weeks. For the many persons with autism involved in this study this service was not believed to be

applicable by staff (N=51). Again persons with autism (N=198) saw a psychiatrist when required (see Figure 5.31).

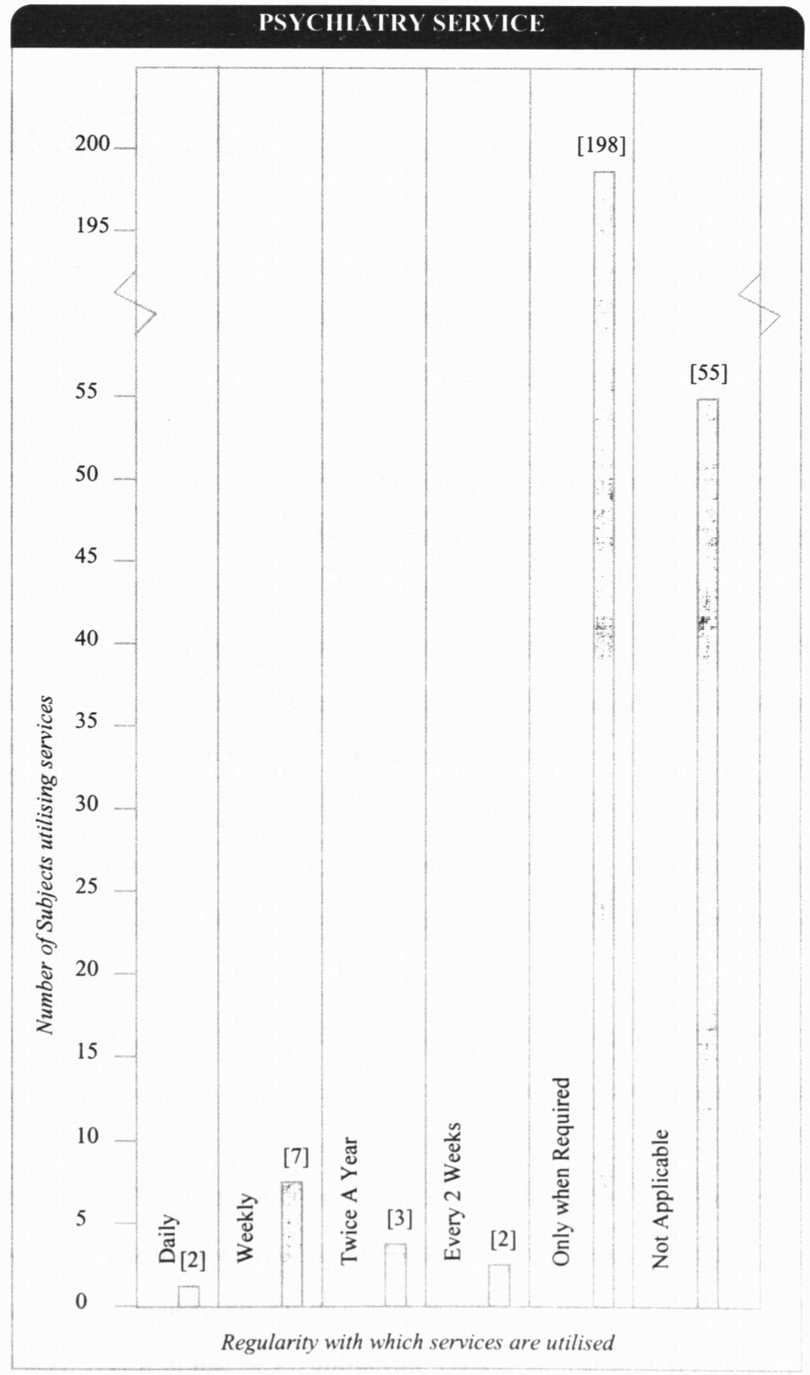

Figure 5.31: The frequency with which subjects utilised psychiatric services (N=267).

The majority of persons with autism in each service setting did have a long term service plan (N=189, 71%). There was no long term service plan for 51 clients (20%) according to the key worker. For the remainder it was not known if they had a service plan for the future.

The following were the main findings concerning parental knowledge of the term autism according to the key worker. Less than half (N=126, 47%) of the staff reported using the term autism when discussing persons with autism needs with parents. A large proportion of staff did not use the term autism (N=118, 44%) and the remainder (N=22, 8%) did not know if the term autism was used with parents.

About half the parents according to the key workers were aware of the client's specific needs which related to his/her autistic disorder (N=119, 45%).

Also 45% (N=120) of the key workers interviewed reported that the long term consequences of a diagnosis of autism had been discussed with the parents. The other parents (N=120, 45%) had not had the long term implications of their child's autism discussed with them by staff or else it was not known if that was the case (N=27, 10%). In addition 142 (54%) of parents had not received information on autism from the service providing agency, but 98 parents (37%) did receive information according to the key workers.

5.23 Family Involvement in Services

The staff reported that 102 families with a person with autism (39%) had access to counselling. According to the staff 77 parents (29%) were in a support group, while 163 parents (61%) were not. Also 35 siblings (13%) of autistic persons were in a support group. Figure 5.32 shows the percentage of families who had access to counselling or were involved in support groups.

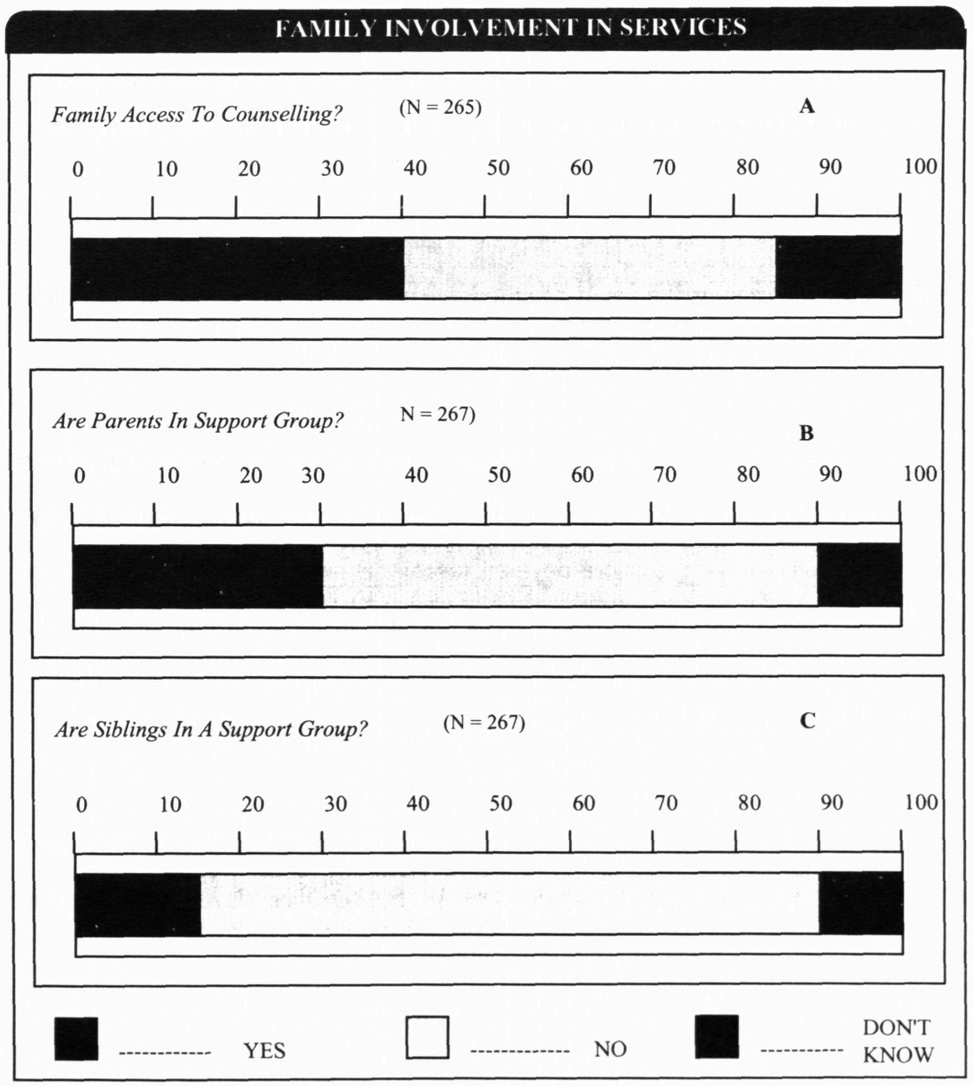

Figure 5.32: The percentage of the staff who reported parents as (a) having access to professional counselling or (b) were in support group, or (c) that siblings are in a support group.

Staff were also asked to provide information on the nature and frequency of respite services available to parents of children with autism. Thirty nine (14%) of families were able to avail of planned relief breaks. Sixteen families had such a break once a year, and another twelve families had a planned relief break twice a year. The others were on a

more regular basis, for example seven families had such a break monthly and the remaining four families had planned breaks weekly. The duration of these breaks were as follows; a week long break (N=11), a two-week break (N=9), a weekend break (N=17) and a break for one night (N=2).

Six families were reported by the key worker to have had a crisis placement, five of these were for a weekend and the another was for a night.

The holiday project available during periods when the day service was closed was availed of by 58 families (21%). For 30 families this meant a day service during school holidays while the other families (N=28) had a day and residential service for this time. These holiday project breaks were on a yearly basis for the majority of families (N=40). However some families (N=18) received them twice a year. The duration of these holiday project breaks were usually for a week (N=36) or for two weeks (N=10).

Two families were involved in a home sharing scheme, this involved having their child placed in a host family usually for a week. One family had this provision on a yearly basis while the other family had such a service monthly.

5.24 Staff Training

The following figure outlines staff training in the area of autism. Of the 219 staff who responded to this question 35 (16%) staff had received no training in the care of persons with autism. One (0.5%) staff member had received undergraduate university training while 50 staff (23%) reported receiving postgraduate university training in the area of autism as a component of their training. The majority of staff reported receiving some form of in-service seminar in the area of autism. Seventeen staff (8%) worked and received training in a service for persons with autism. (Figure 5.33).

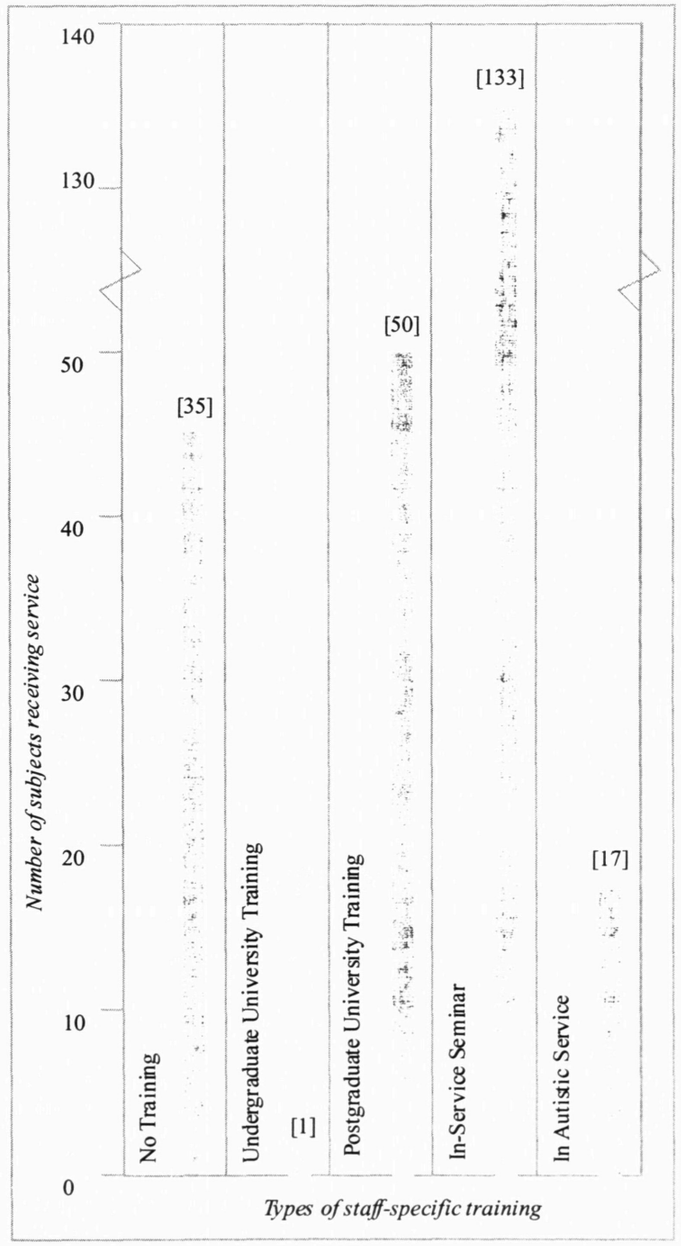

Figure 5.33: The numbers of staff having received no training, some training, undergraduate university training, postgraduate university training, in-service training and training in a service for persons with autism. (N = 219).

Staff were also asked to indicate the suitability of the client's current placement in meeting his/her needs according to the staff working with them; 210 key workers responded. The majority of the key workers felt that the service placement was satisfactory (N=153, 73%), while 30 (14%) said the placement was very satisfactory. A total of 27 key workers reported that the persons with autism's current placement was not satisfactory (N=27, 13%).

Section IV

Chapter Six

Discussion

This study has produced a database of 272 persons with autism as defined by the Autistic Disorders-Diagnostic Checklist of Lorna Wing. It is therefore a very considerable resource for future studies and indeed has greatly facilitated two further studies which are now in progress. There is still considerable discussion about the boundaries of autism. The prevalence rate found in this study is probably an underestimate - because it was not a total population study of all individuals in the E.R.H.A. area up to 25 years. It is probable that some mild cases of autism were missed as well as cases with severe learning disability (mental retardation) who may not have been considered for the autism diagnosis. High functioning cases who may have survived in the normal school system would also have been missed as would cases in the prison system. Other issues which will be discussed in this chapter include gender issues, the importance of varying I.Q. levels, month of birth, and socio-economic issues and epilepsy. The issue of family burden and coping among family members is of considerable importance to service providers. The placement of persons with particularly low functioning autism whether day or residential is a matter of considerable importance. Finally consideration will be given to future research directions.

6.1 Prevalence and Diagnosis

Since all the consultant child and adolescent psychiatrists and consultant psychiatrists in mental handicap were contacted and co-operated in the Eastern Region Health Authority (formally the Eastern Health Board) area there is reason to believe that the majority of those with autism or some features of autism in contact with the agencies studied were referred to us for the research project. There is a good knowledge of autism by these specialists in the Eastern Region Health Authority area. It is a compact area and the specialists regularly meet at professional and academic meetings. There is a unified training programme for all psychiatrists in the Eastern Region Health Authority area. One of the author's (M.F.) who commenced work in the Eastern Region Health Authority in 1971 is familiar with their diagnostic patterns and believes that they have what Gillberg and Coleman (1992) call the required "gestalt acumen" for the diagnosis of autism. The majority of the persons referred to this study were identified in the first instance by them. In addition the Principals (Head Teachers) of the special schools largely specializing in the education of autistic persons were very knowledgeable about autism and made referrals to the study. They regularly attend clinical and academic meetings organised by the Irish Society for Autism and the Department of Health in Ireland. Most of the professions who referred persons for the research were interested in autism. It is not surprising that they correctly identified 272 out of 309 persons when they were assessed using the Autistic Disorders Diagnostic Checklist of Lorna Wing (1987 - Personal Communication).

This Eastern Region Health Authority study presented here had some similarities to Cialdella and Mamelle's (1989) French study in that both used a case - census method.

They used the same kind of locations to identify patients as was used here. The goals of both studies were similar i.e. to increase case collection sensitivity, while remaining within feasibility limits. Like in the Eastern Region Health Authority study they also did not employ formal I.Q. tests because of lack of resources and because this was not the major focus which was the identification of cases with autistic disorder. These studies therefore cannot be compared with studies where formal I.Q. tests were conducted. Like this E.R.H.A. study the patients in this study were not seen directly by the research team which of course precludes generalized conclusions. The age focus of the French study was 3 to 9 years while the Eastern Region Health Authority's study was under 25 years.

Cialdella and Mamelle (1989) believed they underestimated the rate in those with concomitant profound handicaps as these are often considered by professionals as "only mentally handicapped". They also believed that they probably missed less severe cases. Clearly the same factors were operating in the Eastern Region Health Authority study which also underestimated the rate of autism. It is possible that if all the Eastern Region Health Authority patients were reassessed using the Autism Diagnostic Interview of Le Couteur *et al.* (1989) that there would be a certain number of false positives on Autistic Disorders Diagnostic Checklist which would have the effect of reducing the Eastern Region Health Authority rate found. Nevertheless even the ADI-R is not without its problems and it is interesting that the ADI-R (Lord, 1994) was found to be over inclusive with 2 year olds referred for autism. Lord (1991) points out that although parent interviews have yielded information that closely resembled "gold standard" clinical judgements with older children, it is possible that information obtained from observational instruments, rather than parent interviews, may coincide with clinical judgement for very young children with autism (Stone and Hogan, 1993). The French study (Cialdella *et al.*, 1989) was conducted in 1986 while the Eastern Region Health Authority study was conducted in 1990 - 1992. The knowledge of professionals of autism clearly increased over that time so that professionals may have referred more patients for the research project in this Eastern Region Health Authority study.

The study by Brask (1972) used a strategy for identifying children with "childhood psychosis" similar to the strategy used in the Eastern Region Health Authority study described here. She identified children in touch with psychiatric and mental retardation services in Aarhus, Denmark.

A study which differed from Cialdella and Mamelle (1989) and this current Eastern Region Health Authority study was a study by Ritvo *et al.* (1989). Ritvo *et al.* (1989) did interview directly individual potential autistic persons and their families. Ritvo *et al.* (1989) ascertainment procedure was in many ways similar to the Eastern Region Health Authority study. In the Eastern Region Health Authority study one of the author's (M.F.) was a consultant child and adolescent psychiatrist to two special schools with largely autistic children and to one residential unit largely for autistic persons. In the Ritvo *et al.* (1989) study one of the authors had a professional relationship with a school for autistic children before the study started. Ritvo *et al.* (1989) solicited referrals from similar centres to those used in the Eastern Region Health Authority study. It was interesting as well that the population of Utah in the Ritvo *et al.* (1989) study was approximately similar to the population of the Eastern Region Health Authority study. Clearly in studies of this magnitude with well over 1 million of a population it is not possible to interview every member of the population so selections have to be made. Ritvo *et al.* (1989) used

(among others) DSM-III criteria and arrived at a similar prevalence to the Eastern Region Health Authority study.

Bryson *et al.* (1988) points out that most previous estimates of autism derive from epidemiological studies employing case registers, supplemented by screening among professionals. Despite their usefulness, such methods have been shown to yield under estimates (Wing *et al.*, 1976). Clearly though these factors were also operating in this Eastern Region Health Authority study and leading to an underestimate. It would appear therefore if all children in normal schools were screened that the rates for the Eastern Region Health Authority would increase. It would also appear that if all children attending developmental clinics were screened that the rates for the Eastern Region Health Authority would increase. It also appears that if every child and adult under the age of 25 with mental retardation within this total population of the Eastern Region Health Authority was screened then the rate would also increase. Clearly this study is a beginning.

In Steffenburg and Gillberg's (1986) study they suggested that they might have missed "some very young autistic children and a few with very high I.Q. levels". This probably also applies to the Eastern Region Health Authority study.

The fact that Bryson *et al.* (1988) found almost twice as many persons with autism as found in the Eastern Region Health Authority suggests that the Eastern Region Health Authority study was under estimating the rate. The Bryson study of course involved a total population study and involved screening and then individual interviewing of mother and child. Of course the Bryson (1988) findings are now probably also an underestimate because of the findings of Cox *et al.* (1995) study of 18 month olds followed up to $3^1/_2$ years which focussed only on those who did not have severe developmental delay (Baron-Cohen *et al.*, 1996). Gillberg (1995c) pointed out that following this study prevalence rates would have to be revised upwards. While the rate of cases identified has certainly increased from 1966 to 1980s, it appears now that there may well be a further increase in detection rate in the 1990s. This makes sense as it was generally agreed by most epidemiologists that cases of very early autism were being missed from their studies.

It is probable that some cases were considered to only have learning disability and were not considered for autism as well. Ritvo *et al.* (1994) discusses the issue of missed cases in epidemiological studies which is probably also relevant to this Eastern Region Health Authority study. Ritvo *et al.*. (1994) points out that mild cases may not come to clinical attention until adolescence or adulthood. Ritvo *et al.* (1994) goes on to state that definitions requiring the presence of a minimum number or mix of symptoms can preclude the identification of mild cases. They point out that early sensory motor symptoms can abate, developmental spurts can compensate for delays, and cognitive and social defects may become less handicapping with age (Le Couteur *et al.*, 1989; Ritvo *et al.*,1989; Ornitz *et al.*, 1978). These features are probably relevant to this E.R.H.A. study but since it was a cross sectional study it is not possible to comment on changes over time. There may also have been cases in normal schools with near normal I.Q. and also the intelligent Asperger's syndrome patients could have been missed. There could have been a very small number of Eastern Region Health Authority cases treated outside the Eastern Region Health Authority which would also have reduced the final number. The numbers here would likely to be very small. Another group that could have been missed would be those not identified by professional staffing showing any autistic feature.

This Eastern Region Health Authority study of children, adolescents and adults up to 25 years can be compared with a similar study of children conducted in 1974 and published in 1984 when (McCarthy, Fitzgerald *et al.*, 1984) when one of the author's (M.F.) was the research worker using Rutter's (1978) criteria for autism. The survey procedure was again the case-census method and the findings were similar to the present study. Of course neither of these studies studied the total population and so cases not in professional contact were missed. Nevertheless these studies make important starting points. The fact that Lotter (1966) found so few persons with autism in normal schools is not an irrelevant point. It suggests that in Middlesex U.K. using Lotter's criteria in 1966 that autism was uncommon in normal schools using his criteria and method of ascertainment. Certainly the handicaps of more severe autism are not trivial and one would expect teachers to have some inkling that all was not well. Clinical experience suggests that teachers do refer children whom they are puzzled by either directly or though the general practitioner or through the community care doctors (school screening health service) to child psychiatrists.

Since the assessment using the Autistic Disorder Diagnostic Checklist took place in each of the centres there was much discussion with the staff of these centres of any further possible children or adults under the age of 25 and under with autism. There was therefore comprehensive discussion of all diagnostic aspects of autism in each of the centres by the time the study was completed. Cases may have been missed by not contacting ophthalmologists, audiologists and paediatricians although paediatricians work very closely with child psychiatrists in the Eastern Region Health Authority and refer all cases of possible autism to child psychiatrists. It is likely that this database does not contain all cases with autism. More recent studies have shown higher rates of autism than 10 years ago (Gillberg *et al.*, 1991). In addition it is possible now that the rates of autism are even higher than ever previously recorded following the studies of general population of Baron-Cohen *et al.*, 1996 - although this was not strictly an epidemiological study according to Cox *et al.*, 1995.

The Autistic Disorders Diagnostic Checklist was developed by Dr. Lorna Wing to provide a revision of the diagnostic criteria for autism used in DSM-III (APA, 1980). She was qualified possibly more than anyone else in the world at the time to carry out this task having developed the triad of impairments characteristic of autism - impairments in social relatedness communication and imagination (Wing and Gould, 1979). The Autistic Disorders Diagnostic Checklist identifies these core features of autism. On the Autistic Disorders Diagnostic Checklist positively diagnosed children also meet Rutter's (1978) criteria for autism with the exception of the requirement that diagnosis be made before the child is 30 months of age.

Another strength of the Autistic Disorders Diagnostic Checklist was that at the time that it provided instructions on how to use the checklist clearly. Clearly these were not as detailed as the guidelines for the more recently developed Autism Diagnostic Interview (Le Couteur *et al.*, 1989).

This E.R.H.A. study could also be criticised because the diagnostic criteria were quite broad and what was being identified were autistic continuum disorders or autism spectrum disorders. False positive results are more likely using broad criteria. Diagnostic criteria would appear to have an influence in prevalence rates and in this E.R.H.A. study there was considerable variability in rates between the Autistic Disorders

Diagnostic Checklist (Wing, 1987 - Personal Communication) criteria and Kanner's 5 criteria. Nevertheless there are some points in favour of this broad approach. Rutter *et al.* (1993) states that the genetic data clearly point to the need to widen the diagnostic concept, but the data do not yet provide a precise set of criteria. There is a need to identify which cognitive deficits associated with autism apply similarly to effected relatives of normal intelligence with the broader phenotype. Nevertheless they also point out "that autism proper differs from the broader phenotype with respect to associations with epilepsy, mental retardation and possibly head circumference". They point out that the autism phenotype extends beyond the traditional diagnostic boundaries and that this is supported by twin and family studies. They acknowledge the continuing discussion on where and how the diagnostic boundaries should be drawn (Rutter and Schopler, 1988, 1992). Clearly the actual boundary of autism is an open issue and there is support for a broader phenotype. This is well put by Wing (1993) when she states that typical autism is just one subgroup in a continuum of disorders involving social and communication impairments that are lifelong in their effects although they vary in their severity from profound to minimal and subtle but still detectable. In discussing DSM American Psychiatric Association (APA, 1994) and ICD World Health Organisation (WHO, 1993) classifications Aarons and Gittens (1992) point out that the latest additions of both classifications recognise disorders wider than classical autism which both call Pervasive Developmental Disorders. They point out that these "are roughly equivalent to the continuum of disorders in which Wing's triad of social and communication impairments occur". They believe that the proliferation of subgroups "can lead to a proliferation of labels which is likely to confuse rather than clarify the diagnosis". Frith (1991) point out that in defining clinical categories two kinds of errors are common:

(1) The categories are too small and leave the majority of patients unaccounted for, or

(2) Too large and do not differentiate patients who in most clinicians opinions present different kinds of problems.

Another point in favour of the autistic continuum was when PDDNOS persons were compared with language disordered persons (Mayes *et al.*, 1993) that children with PDDNOS resembled children with more classical autism than those with language disorder. This supports to some extent Gillberg and Coleman's (1992) view "that there appears to be a spectrum or continuum - of autistic syndrome or autistic disorders. Any cut off between the various subcategories on this spectrum at the moment appears to be relatively arbitrary".

While Wing and Gould's (1979) autistic continuum has autistic disorder DSM-III-R (APA, 1987) at one end and PDDNOS at the other end, Tsai (1992) is critical of this and states that "it would be unsatisfactory to bury these subgroups in the undifferentiated fashion such as the approach adopted by DSM-III-R (APA, 1987) and the autistic continuum". Tsai (1992) favoured the "splitters" approach of ICD-10 (WHO, 1993).

While the issue of subtyping of autistic spectrum disorders is not yet clear one family one of the author's (M.F.) has treated had a number of different subtypes in the same family (Bowman, 1988). Clinically one of the author's (M.F.) has observed this many times. There is therefore some suggestive (clinical) support for it.

Wing (1993) makes the extremely important point that there is no "clear-cut boundaries between typical autism, atypical autism and other manifestation of the triad" of

impairments in social interaction, communication and imagination. She concluded that "the possible total prevalence of those of any level of intelligence with the triad of social impairment, referred to as the "autistic continuum" (or perhaps more appropriately "autistic spectrum") may be as much as 47/10,000. It is likely that the new findings by Baron-Cohen *et al.* (1996) in pre-school children will inflate this figure further. It is difficult to know when this rise in prevalence rates that has continued since 1985 will end. It is likely that if this population based (although not complete) study in the South of England by Baron-Cohen *et al.* (1996) had been used in this E.R.H.A. study with pre-school children the final prevalence figure would have been much higher. The lack of "clear-cut boundaries between autism, atypical autism and other manifestations of triad" would support the use of the Autistic Disorders Diagnostic Checklist of Lorna Wing as satisfactorily identifying these patients. Clearly genetic studies as already described (Rutter *et al.*, 1993) also support the broader phenotypes.

Volkmar (1992) commented that in the absence of an absolute marker or "gold standard" the issue of whether the broader (DSM-III-R) or narrower DSM-III and ICD-10 view of the disorder is preferable is a matter of judgement. He said that part of the problem was that the broader concept reflected a failure to include other disorders with the PDD class and the inclusion of other diagnostic concepts might allow a more stringent definition of autism.

Shea and Mesibov (1985) have pointed out that classical cases are greatly outnumbered by cases with "mixed, impure and partial characteristics". Gillberg and Coleman (1992) favour the label autistic syndromes of childhood. It seems to be a good label. Gillberg (1992a) also points out that Kanner autism does not have more validity than any of the other named syndromes on the autistic spectrum. This is a far cry from Kanner's original belief that autism was a single disease (Coleman, 1990). She points out that the concept of autism as a syndrome gradually unfolded (Coleman, 1976) and that today autistic syndromes are seen as age related expressions of improper developmental programming of the brain (Coleman and Gillberg, 1985).

It is possible that Kanner's criteria happen to be found mainly in those who are mildly to moderately retarded and age between 4 and 12 years of age not because the criteria define a separate syndrome but because the level of cognitive ability determines the way in which the triad of social impairments is manifested (Wing, 1993).

Subtyping of autism was not the purpose of the Eastern Region Health Authority study. The aim of the study was to identify patients meeting a diagnosis of autistic disorder using the Autistic Disorder Diagnostic Checklist as well as to examine associated psychosocial factors. There is considerable problems with subtyping and indeed a recent subtyping exercise (Eaves *et al.*, 1994) using cluster analysis found 4 subtypes which were different from the subtypes of DSM-III (APA, 1980) and DSM-III-R (APA, 1987). Eaves *et al.* (1994) study supported concerns others have voiced about the usefulness of a diagnostic scheme that requires an arbitrary number of symptoms and only partially considers developmental level (Siegel *et al.*, 1990). In the Eaves *et al.* (1994) study "none of the DSM-III-R characteristics could be used to distinguish the subtypes, chiefly because the children with autism - PDD had them (e.g. lack of peer friends), or because so few did (e.g. failure to seek comfort) or because they were related to cognitive or verbal ability (e.g. no verbal communication)". Siegel *et al.* (1990) also noted the redundancy of the DSM-III-R characteristics. They found the criterion of "marked lack of

awareness of others" to be the only relevant criterion; the others co-occurred so frequently as to be redundant. Siegel *et al.* (1990) argued that a smaller number of defining criteria, noting associated features and providing clear definitions of intelligence or mental age, is required to improve the precision of an autism diagnostic scheme. Obviously, low functioning children or very young children cannot be rated on some items, hence require a higher proportion of items in order to be considered autistic. Clearly subtyping is a fertile area for further research. Because of this Rutter and Schopler (1992) point out that "there is a lack of clear cut guidance on whether a narrower or broader diagnostic approach is to be preferred". Rutter and Schopler (1992) also point out "that within all three classifications (DSM-III, DSM-III-R and ICD-10) it is necessary to consider the possibility that the particular criteria used for subdivision might prove to be mistaken. To a degree that is almost certain to be the case". They also point out "that it is highly undesirable for research to be constrained by any one classification system". They were keen that the overall provision for PDD was broad and that the terminology provided links with autism. In addition they point out that "in the past DSM has sought to provide rules for all categories but it is necessary to recognise that in many instances we lack the data needed to formulate such rules and it is desirable to be quite explicit in making overt our ignorance". Clearly it is the profoundly retarded young children where there is the greatest danger of false positives (Rutter and Schopler 1992). This was an issue for this Eastern Region Health Authority study. Further evidence of the problems of subclassification were shown by Dahl *et al.* (1986) when they were unable to distinguish COPDD (Childhood Onset Pervasive Developmental Disorder) from autistic spectrum disorders using cluster analytic methods. While Rutter and Schopler (1988) argue that autism is a valid and meaningfully distinct syndrome Waterhouse and Fein *et al.* (1987) and Waterhouse *et al.* (1989) argue that there are serious boundary problems for autistic disorder versus PDDNOS and versus other disorders. A far more critical comment was made by an editor of the Journal of Child Psychology and Psychiatry Dorothy Bishop (1995) when she stated "the label PDDNOS can only be regarded as a carbuncle on the face of child psychiatry".

Wing (1993) concludes that the rates cannot be attributed to different diagnostic criteria but that different interpretations of diagnostic criteria could be significant. She believed that real variations in the prevalence of autism existed. Wing (1979, 1980) found a rate of Kanner's Autism among children whose fathers were British or from Western Europe to be 4.4 / 10,000 and 6.3 for children whose fathers were first generation immigrants from third world countries. The rates for autistic-like conditions were 9.9 and 37.8 respectively. In addition (Gillberg, Steffenburg, Borjesson *et al.* 1987; Gillberg, Schaumann *et al.*, 1991) found children with autism (typical and atypical) were more likely to come from "exotic" countries like Asia, South America or South-East European countries. This has relevance for this E.R.H.A. study as Ireland had an extremely low immigrant population and none of persons with autism came from an "exotic country". This lack of a significant immigrant population could have slightly depressed the prevalence rates for autism as compared to Sweden or U.K. Indeed Ireland had a long history of a very large immigration from the country. It is unknown if this large out immigration rate has any effect on autism rates. Gillberg (1995a) has stated that "the 'classic' Kanner autism behavioural phenotype may show a stable prevalence rate in non-immigrant populations".

There has also been discussion in the literature (particularly in relation to the increased rates of autism in immigrants) about the possible contribution of intra-uterine viral

infections. Gillberg (1990b) found indirect support for this as children with autism in Gothenburg were more likely to be born in March and that March born cases came from poor social conditions, increasing the risk of pregnancy viral infections. This E.R.H.A. study did not find any particular month to be more common than others.

It is worth considering this E.R.H.A. study in the light of two very comprehensive analyses of epidemiological studies of autism (Wing, 1993; Gillberg, 1995a). It belongs to a series of studies which have not for example conducted "more thorough" screening (Gillberg, 1995a) of the general population. Other examples include Steinhausen *et al.* (1986) which used only two sources in their screening programme i.e.

a) A university clinic for child psychiatry, and

b) A centre providing a programme for children with autism.

Another example is Fombonne *et al.* (1992) who made diagnosis based on case notes of children known to specific services. At the same time this E.R.H.A. study did use the instrument Autistic Disorders Diagnostic Checklist of Lorna Wing which met Rutter (1978) criteria. This E.R.H.A. study did not use subjective judgements. A previous E.R.H.A. study (McCarthy *et al.*, 1984) asked child psychiatrists and staff of relevant institutions for names of children diagnosed as autistic. This current E.R.H.A. study searched for children and adults under 25 years with any feature of autism.

Those in prisons or secure hospitals were also missed in this E.R.H.A. study. It is interesting to note that Scragg and Shah (1994) found a prevalence of 1.5% (0.6% to 3.3%, 95% C1.). When they added equivocal cases this in creased the prevalence of Asperger's Syndrome in Broadmoor (Secure) Hospital in the United Kingdom to 2.3%.

Clearly this current E.R.H.A. study was widening the net for persons with possible autism when compared to Treffert (1970) study which only examined information from computer print outs on cases diagnosed as suffering from "childhood schizophrenia".

Gillberg (1995a) concludes that if the "psychotic behaviours" or "autistic features" shown in some mentally retarded children (Wing and Gould, 1979; Gillberg *et al.*, 1986) and children with DAMP (Gillberg, 1993) "are included in the 'autism spectrum group' then it appears that we may be dealing with another half of a percent or so of the general population of school-age children". For Gillberg (1995a) "the combined rate of autism, Asperger Syndrome, and other autistic-like conditions is, at least ten times that reported for 'autism' in the older studies".

One of the short comings of traditional diagnostic systems in the past was that they required arbitrary decisions about, for example, the degree of a child's social responsiveness, in the absence of operational criteria. Nevertheless in this Eastern Region Health Authority study the Autism Disorders Diagnostic Checklist did possess the core characteristics of autism. Of course the newer diagnostic instruments possess much more operational criteria.

It is of interest that the items which were rated most frequently on the Autistic Disorders Diagnostic Checklist were relationship items as one would expect when the people in question were people with autism e.g. items which rated between 75% and 87% frequency included:

(1) Self chosen activities are solitary.

(2) Indifferent to others.

(3) No peer friendships.

(4) Invades others personal space.

The Vineland Maladaptive Domain also identified items which can be features of autism e.g.:

(1) Poor eye contact 68% of cases.

(2) Withdrawn in 75% of cases but this does not allow one to state whether they fitted into Wing and Gould's (1979) aloof group.

(3) Lack of consideration for others in 74% of cases.

The diagnosis "autistic tendency" in 26.4% is not a satisfactory diagnosis because a person either has an autistic spectrum disorder or does not have an autistic spectrum disorder. The diagnosis "autistic tendency" would appear to leave the diagnosis uncertain which would have negative effects for parents, professionals and service planners. The "diagnosis of autistic language" is equally unsatisfactory as it suggests all that is required is language therapy. In addition autistic language is not a formal diagnosis. Fifty two per cent (52%) of parents reported receiving no diagnosis. This does not allow one to state definitely whether they received a diagnosis or not as they may have forgotten it or misheard or a definite diagnosis may not have been made. The absence of a diagnosis makes it difficult for parents to know exactly what they are dealing with and leaves them with a good deal of uncertainty. The diagnosis also has significant implications for treatment and research.

The method of diagnosis could be criticised because it used only the principal or key worker with the potential autistic person. Nevertheless the Autism Diagnostic Interview (Le Couteur *et al.*, 1989) one of the most widely used instruments today is administered to the subjects principal caretaker with satisfactory results. In another context Rutter's *et al.* (1981) parental interview to assess psychopathology in children was also administered to the principal caretaker satisfactorily (Jeffers and Fitzgerald, 1991). Adolescents (with non-autistic psychopathology) in particular need to be interviewed directly.

At the same time there is now an additional tool which will be useful in future studies. It is the Autism Diagnostic Observation Schedule of Lord *et al.* (1989).

It is interesting that the Index of Social Competence by McConkey *et al.* (1982) specifically states that this index should be completed "during an interview with a person with whom the handicapped person - probably a parent or guardian if the person lived at home or the staff member with whom the person had most contact or who knew him or her longest". This is precisely the method used in this E.R.H.A. study. It is also of interest that McConkey *et al.* (1982) specifically state that the information for the Index of Social Competence is to be acquired from "the staff member with whom the person had most contact or who knew him or her the longest". Indeed when a check was made

comparing the ratings made by parents and by staff McConkey *et al.* (1982) there was a 75% agreement for communication skills; 78% agreement for self care skills, and 72% agreement for community skills. Indeed Lambert (1978) noted comparable results with the Adaptive Behaviour Scale. Lambert (1978) makes the point that the best respondents are those who have direct involvement with the mentally handicapped person in all the ability domains scored by the index. At the same time Leland (1972) points out that there may be real differences between the level of functioning at home compared with school or day centre.

McConkey and Walsh's (1982) conclusion was that there was "a reasonable degree of correspondence between ratings made by families and those of staff".

Children with autism can show different degrees of problems in different settings and assessment of behaviour in one setting cannot be assumed to represent performance in other settings. Kazdin (1995) notes the moderate correlation between parent and teacher ratings of emotional and behavioural problems in children. Clearly the perspectives of different individuals across different settings is important as part of the clinical picture. Koot (1995) points out that parent confirmed psychopathology was more persistent than non-confirmed. Of course this point is less relevant for such a persistent disorder as autism. There is little doubt that the best studies of child psychopathology rely on different informants because reliability can be established and the validity of reporting is usually higher. Caution has to be exercised as not all informants have the same opportunity or skills of observation (Loeber and Farrington, 1995).

As Achenbach (1995) points out no single source can substitute for all relevant sources of data. He has developed a paradigm called "a multiaxial empirically based assessment and taxonomy (MEBAT) for co-ordinating data for multiple sources". Achenbach's (1995) view is that rather than treating discrepancies among sources as error, MEBAT uses them to reveal variations in childrens functioning in different contexts as judged by different informants. Clearly different informants will complete the clinical picture. At the same time autism is a severe condition and particularly in this E.R.H.A. study where the persons with autism were tending in the direction of lower functioning it would be unlikely that they would be mistaken for persons with no psychopathology.

Nevertheless it has to be acknowledged that information from multiple informants would have strengthened the diagnosis. Szatmari *et al.* (1994) found that on the Vineland Adaptive Behaviour Scales (Sparrow *et al.*, 1984) there "was good agreement between parents and teachers on each measure" but that teachers tended to rate PDD children higher than parents. They also found that adaptive skills appear to show more stability across settings than do reports of autistic behaviour. There is therefore a need for a further study of the use of the same diagnostic instruments in different settings with different informants and with the autistic person themselves where possible (i.e. high functioning persons with autism and language).

It is interesting that Wing (1993) in her review of the prevalence of autism selected for persons with autism used the following as one of her criteria of identification "by the direct care clinical staff who provide information requested by the authors as part of the study". Dr. Lorna Wing in her instructions on how to use the Autistic Disorders Diagnostic Checklist states the information should be acquired from "the teacher, paediatrician or other who knows the child best". Once again this particular identification method is similar to the one used in this Eastern Region Health Authority study. This

Eastern Region Health Authority study would be excluded from Wing's 1993 review because the initial selection was made by asking child psychiatrists, educational staff and other health professionals of the relevant institutions for the names of children with any autistic features.

In a separate study not connected with this Eastern Region Health Authority study but using names of identified patients from this E.R.H.A. study database 50 out of 50 met criteria for autism using the DSM-III-R criteria (APA, 1987) (Patricia Buckley, 1996 - Personal Communication). In addition in another on going study also involving two of the authors (M.F. & P.M.) 15 patients out of 15 met DSM-IV (APA, 1994) criteria for autism (Patricia Coulthard, 1996 - Personal Communication). These two studies which are ongoing made the selection from the 272 originally identified by the Autistic Disorders Diagnostic Checklist in a fashion that suited the two following studies which meant they were selected in a non-random fashion and of course the numbers were also small. These two currently progressing studies do not of course offer any proof that the 272 had autistic disorder. What they show is that at least of the cases re-examined they all met currently recognised criteria for autism.

The findings of the Eastern Region Health Authority study in terms of prevalence of autism fits well with previous research findings. Lord and Rutter (1994) in reviewing epidemiological studies in autism in a prestigious British textbook of child and adolescent psychiatry came to the conclusion that "the prevalence of autism is now estimated at 2 - 5 per 10,000". If replication of findings is one way that science advances then the finding of this Eastern Region Health Authority study must be given some weight with qualifications. Indeed Ritvo *et al.* (1989) pointed out that surveys which are close to previously published estimates around the world support its validity. This will not hold if methodology including methods of ascertainment change. Nevertheless the authors are satisfied that a rate of 2 - 5 per 10,000 is now an underestimate.

It is also interesting that Volkmar (1991) writing in a prestigious American textbook of child and adolescent psychiatry came to a similar conclusion. He writes "it is noteworthy that available research is in general agreement regarding the prevalence of autism. If autism is a more strictly defined, prevalence rates of two cases per 10,000 are usually reported; less stringent definitions typically suggest prevalence rates of 4 to 5 cases per 10,000 (Zahner and Pauls, 1987)".

At the same time one has to acknowledge obvious difficulties in this area of research. Clearly results of epidemiological studies are very dependent on the methods used and the diagnostic criteria used and this E.R.H.A. study was not a general population study and therefore cannot be generalized to representing the prevalence of autism in the general population.

The epilepsy rate was 22% (9% problematic, 13% not problematic) in this Eastern Region Health Authority study deserves comment. This 22% epilepsy in autism rate in autistic disorder is greatly in excess of the general population rate of 0.5% (Corbett, 1983). Gillberg and Coleman (1992) point out that "epilepsy in classic forms of autism is reported in between 1:7 and 1:3 children, the frequency rising according to the length of the follow up period". They point out that the average rate for adults with autism is 25 - 35% with epilepsy. Of course in the Eastern Region Health Authority study some of the persons identified with autistic disorder were children. One would expect the epilepsy

rate particularly in these children to increase as they get older. The increase in the epilepsy rate occurs around puberty. The subcategorization of epilepsy was not a goal of this Eastern Region Health Authority study. In the culture in which the Eastern Region Health Authority study was conducted "fits" mean epileptic fits. It is possible that a research study in E.R.H.A. focussing exclusively on epilepsy and autism in a very detailed way like Olsson Steffenburg and Gillberg (1988) would find higher rates of epilepsy. It may be difficult to diagnose psychomotor seizures in the autistic adolescent because of his already disturbed behaviours. A seizure disorder would be suggested by suddenness of onset, associated facial or other involuntary motor movements, or alterations in level of consciousness after the suspected seizure.

It is interesting that when severe mental deficiency and motor deficits were excluded Tuchman *et al.* (1991) found an epilepsy rate in autism of 7%. He concludes that "once the risk attributable to associated cognitive and motor disabilities is taken into account there is no difference in the risk of epilepsy between autistic and non-autistic dysphasic children". There is conflict in the literature between Gillberg and Coleman (1992) who state "that the connection between autism and epilepsy might be rather specific, and not only mediated via common denominator of mental retardation" and Tuchman *et al.* (1991) who states that "autism in and of itself is not an additional risk factor for developing epilepsy". Nevertheless Gillberg and Coleman (1992) note "the association of autism with epilepsy in the absence of mental retardation". They conclude and this is relevant to this Eastern Region Health Authority study that "the large reported variability in the number of autistic children with epilepsy is likely to be due to differences in associated disabilities among the population studied".

The issue of epilepsy in autism played a part in moving the discussion of the aetiology of autism from a psychogenic and psychoanalytical perspectives to biological theories of aetiology. Happe (1994) points out "that one indication that brain damage is at the root of autism is the high incidence of epilepsy in autistic children" (Olsson *et al.*, 1988).

6.2 Gender Issues

It is difficult to explain that the male:female ratios were almost 4:1 in the 6 - 15 years age group and under 2:1 in the 16 - 25 year old group. One could speculate that there is some kind of age effect operating here. It is possible that some female autistic persons under 15 years are passive (Wing and Gould, 1979) and are not considered to be autistic because passivity might be seen as a more female trait. It is possible that boys are expected to be culturally more active and therefore passivity in them is seen more quickly as abnormal. It would then be necessary to speculate that as females got older that this passivity trait was no longer seen as appropriate and so a diagnosis of autism would be considered. Kopp and Gillberg (1992) have hypothesized that one of the reasons for the low rate of typical autism in females could be the fact that the gestalt of the autistic syndrome has been evoked for the male 'prototype'. These authors go on to state that "the same type of condition could occur in girls, but with a slightly less typical "male" symptomatology. From the findings of the Eastern Region Health Authority study it would then be necessary to speculate that this "male stereotyping" was more likely to happen in those under 15 year olds. Another possible explanation would be that the almost 4:1 male female ratio in those under 15 years might be due to these being at the more able end of the autistic continuum. I.Q. was not studied in the Eastern Region

Health Authority study so it is not possible to comment on this from a scientific point of view. Wing (1980) has documented that the over representation of boys with autism is less pronounced in the severely retarded group. Gillberg and Coleman (1992) have suggested "that these trends could suggest that whereas boys are (genetically?) much more prone to developing autism, more severe brain damage would be required for the development of autism in girls". Steffenburg and Gillberg (1986) found a sex ratio of almost 3:1 for boys:girls. The Eastern Region Health Authority 0 - 15 years was under 4:1. Certainly these two figures are closer together than Wing's (1981c) ratio of 15:1 at the higher level of ability. In Lord *et al.* (1982) girls came out worse when daily living skills were assessed. One might speculate that these were more important and visible in older females than female children in the Eastern Region Health Authority and therefore were given a diagnosis of autism more quickly. Frith (1989) points out that the excessive numbers of boys found in all studies and the scarcity of girls at the middle and higher ability levels are typical "clues" to the biological origin of autism. McLennan *et al.* (1993) states that there is no evidence that females are generally more "autistic" than males. They felt it was still possible that different modes of transmission might be operating in the families which only males are affected than in families with an autistic female (Spence *et al.*, 1985). Wing (1981c) suggested that sex differences reported in normal populations such as male superiority in visuospatial tasks and female superiority in language skills, may contribute to the sex differences in the incidence of autism.

It is of note that in this E.R.H.A. study a passive role in play was identified more frequently in males than females. This might again suggest that a passive role in play is identified as being more abnormal in males than females. It is difficult to speculate why abnormality in pitch, stress, rate, rhythm or intonation was more frequent in females but one might speculate that abnormalities in use of speech might come to attention more quickly in females. It is possible in our society that females are expected to have better use of speech than males.

Frith (1989) points out that boys in terms of the "ability to relate to people, girls were as poor as, but not worse than boys". This E.R.H.A. study suggests that males were significantly more indifferent to others than girls as well as taking a more passive role in play. One can agree with Frith (1989) when she states that "it would not be right to think of girls in this study (Lord *et al.*, 1982) as more 'autistic' than boys".

One might speculate that in this E.R.H.A. study particularly in the 16 - 20 year olds and to a lesser extent the 21 - 25 year old persons that there was some characteristic that drew the attention of staff in the first place (i.e. before the administration of the Autistic Disorders Diagnostic Checklist) as possibly having autism. This would require further research and could possibly give some clue to the sex differences.

6.3 I.Q.

This was not studied in the total sample due to lack of resources as formal assessment of 272 persons with autism would require a great deal of additional resources. Of course many other studies of autism likewise and for the same reason were unable to conduct formal I.Q. or educational tests (e.g. Cialdella and Mamelle, 1989). At the same time this E.R.H.A. study has considerable information on levels of competence; independent living skills and some information on reading and writing competence from the Index of Social

Competence. While the formal I.Q. score is predictive of long term outcomes, placement decision matters often place as much weight on social adjustment.

McConkey and Walsh (1982) point out that although I.Q. scores offer an apparently objective measure, more critical appraisal has identified numerous problems - they are liable to a high degree of measurement error especially at the lower levels; the same I.Q. on different tests may not mean the same thing; even the same I.Q. on the same test could mean different things due to restandardizations.

Adams (1973) points out that a more serious consequence of this emphasis on intellectual assessment is that the equally important criterion of impaired social adjustment - which is included in all definitions of mental handicap - is being over looked.

The following point by Clarke *et al.* (1974) is also relevant to persons with autism and mental retardation (learning disability). Clarke *et al.* (1974) point out that "social adjustment is particularly important as a qualifying condition of mental retardation at the adult level when it is assessed in terms of the degree with which the individual is able to maintain himself in the community and in gainful employment as well as his ability to meet and conform to other personal and social responsibilities and standards set by the community".

6.4 Month of Birth

This E.R.H.A. study found no particular month or season of birth which showed an increase over any other month or season of birth. A number of other studies have found an excess in the summer months and the month of March (Barlick, 1981; Konstantareas *et al.*, 1986; Burd, 1988) and Gillberg (1990b) found an excess in the month of March. In this E.R.H.A. study it is the first time that this has been looked at in an Irish population. The reasons no increase has been found could be again due to:

(1) Diagnostic criteria.

(2) A chance finding.

(3) Different infectious agents being prevalent in other countries.

It is unlikely that there is any enormous difference between infectious agents in Ireland and other European countries.

6.5 Socio-economic Distribution

This study found no social class differences in the rates of autism. Nevertheless Sanua (1987a, 1987b) discussed a possible bimodal distribution of socio-economic status among families of persons with autism. Most of the most recent studies from France, American and Sweden show no class bias among persons with autism. A study which did show such a slight class bias was that conducted by Lotter (1966). Gillberg (1990a) makes the following comment on the data concerning such class differences: It could be that high level of autism and Asperger syndrome are correlated with high social class .... If this

turns out to be the case, then the link is likely to be an indirect one. High parental I.Q. - correlating both with high social class and relatively higher I.Q. in the child with autism - could be the source of the association. Each of the following studies has indicated that no social class bias exists (Brask, 1970; Wing, 1980; Gillberg & Schaumann, 1982; Bohman *et al.*, 1983; Steffenburg and Gillberg, 1986; Cialdella and Mamelle, 1989, 1989; Logdahl, 1989; Gillberg *et al.*, 1991).

When social class is taken as a variable in examining the epidemiological findings, the picture is very unclear as to its role. Zahner and Pauls (1987) point out that in this regard the findings have been non-conclusive and conflicting and that further studies are required to examine if there is any relationship between social class and autism. Gillberg and Coleman (1992) stated that "the possibility remains that among the relatively brighter children with autism, social class might be somewhat higher. This in turn, might mean no more than that among the normal child population high intelligence and high social class show some correlation".

6.6 Family Burden

It is clear that mothers perceived the families as experiencing very considerable burden because of the person with autism. Many families (67%) had the experience of a leisure activity being abandoned because of the person with autism and for 41% this was a moderate burden while a further 26% found it as a severe burden. Leisure and holidays would be seen as a right by most people in western society but in this study mothers stated that there was a moderate burden on the family in 33% of cases and a severe burden in 30% of cases where there was a person with autism because the person with autism was using up another persons holiday and leisure time. In addition 79% of the families experienced extra expenditure due to the person with autism which was regarded as a moderate burden by 41% and a severe burden by 19%. This E.R.H.A. study also suggests that the need for extra financial resources needs to be examined particularly for those families with limited financial resources. In this study extra expenditure to pay for extra care giving due to the person having autism was described as a moderate burden by 41% of mothers and a severe burden by a further 19% of mothers. As can be seen from the results there was considerable extra stress (burden) in the areas of disruption of family activities; family interaction; effects on physical and mental health of family members as well as additional financial burdens. These suggest interventions need to be made at the clinical level and researched in a scientific way. The risk of social isolation of the family of a person with autism needs to be addressed with 47% of mothers stating that the experience of relatives and neighbours stopping or reducing their visits to the family as being experienced as a moderate or severe burden. It appears that their needs for social support or their social needs being met through interactions with others (Kaplan *et al.*, 1977) needs to be examined.

In this E.R.H.A. study a support group might have helped but only 30% of parents were in such a support group. Support groups can help parents or siblings to normalize their emotional reactions as well as supporting each other particularly in families with a person with autism where there is a tendency for social isolation. This E.R.H.A. study suggests that social contact variables are very important.

Jeffers and Fitzgerald (1991) showed in the E.R.H.A. area that it was the isolated mothers who were particularly likely to show formal depression and to have children with definite

psychopathology using formal clinical interviewing. A support group would also allow parents to share successful management strategies in relation to behaviour problems of persons with autism. These groups could also help parents with negative attributional styles to alter these. The groups could also help parents to come to terms with autism and relieve some of the guilt they may feel about not giving sufficient attention to their other children.

It is worth remembering that Schaefer *et al.* (1981) found that emotional and tangible support was linked to psychological health while informational support was not. This provides a challenge to the community, voluntary agencies as well as professional organisations in delivering better social networks for families with persons with autism. It is of interest that Bristol and Schopler (1983) found that 70% of children of families experiencing high levels of stress were receiving service provision which by and large did not provide parent support services. It is also worth remembering that it is not necessarily true that services will be supportive of parents and Schopler and Loftin (1969) and Turnbull *et al.* (1978) have noted that some services might even be a source of stress to families.

It is possible that if the family perceive the person with autism more negatively than the degree of handicap would warrant they may experience increased burden and poorer adaptation of the family (Bristol, 1987; Gill, 1990; Fong, 1991). This requires more detailed study. It is possible that mothers with a more optimistic attitude to life may be less burdened (Brewin and MacCarthy, 1989). Family cohesion was an issue not addressed in this E.R.H.A. study. It is possible that excessive closeness or enmeshment or excessive distance and detachment between family members could also increase the level of burden of dealing with a person with autism. It is also of interest that Procidano and Heller (1983) found that perceived social support from friends was clearly related to social competence of the individuals receiving the support. This suggests that mothers of persons with autism who were more socially competent would be more likely to perceive their friends to be socially supportive. It is also possible they may be more likely to engage their friends for the purposes of social support. There is evidence (Procidano and Heller,1983) that people with perceived high levels of social support from friends were more open in talking about themselves to friends. This again shows how complex the social contact variables are in this E.R.H.A. study and the need for further study.

There was also considerable effect on the family atmosphere in the home and indeed family members got into arguments over the management of the person with autism which was described as causing moderate burden in 28% of families and severe burden in 17% of families. This suggests the need for the development of new strategies of intervention at the family level. While considerable progress has been made in this area (Mesibov *et al.*, 1983; Howlin 1980; Lovaas 1980, 1987) although Lovaas outcome measures have been questioned (Schopler *et al.*, 1989) it would appear that if family members are to agree on the management of a person with autism they will need accurate diagnoses and a detailed understanding of autism. In this study 52% stated that they had not received a diagnosis. Crnic *et al.* (1983) and Turnbull *et al.* (1984) point out that the families beliefs and perceptions about handicap and related issues maybe central to the coping strategies they evolve. One can only speculate about why some families experience lower levels of burden - this may be due to the families being more "close-knit", able to "role with the punches", and able to adjust as the persons need change (Bristol and Schopler, 1983).

When mothers were asked about the subjective burden on the family 42% described this as moderate and 53% described it as severe. This equates with the authors experience of clinical reality and would appear to have relevance for persons who come into contact with families with an autistic person. This knowledge should help them to increase their level of empathy.

6.7 Levels of Stress on Mothers

The level of stress on mothers can be seen from the finding of 43% of them being constantly under strain, and 30% "been taking things hard", and 25% "finding life a struggle all the time", and 29% finding "everything on top of you". About one third scored at 5 or more on the General Health Questionnaire. These mothers experienced significant social problems including difficulties in confiding in their partners; problems in their sexual relationship as well as being more likely to consider separation and finally experiencing more difficulties with their other children.

It was expected that social contact variables would differentiate the "poor psychological health" mothers from the "good psychological health" mothers. This indeed emerged. The "poor psychological health" mothers group of mothers of persons with autism did not have as much contact with their family as compared to the "good psychological health" mothers ($t = -2.13$; $df = 66$; $p > .05$).

Indeed 36% of the mothers said they were constantly tired. They also showed significantly increased levels of burden on the family burden schedule including more disrupted family interaction and family leisure. This was quite a strong finding. From a statistical point of view the state of the marriage was of very considerable importance in differentiating poor health mothers from good health mothers. It is possible that a good marital relationship provides considerably increased cohesiveness in the family and increased resources in coping with the person with autism. It is also possible that a very difficult person with autism could put a marriage under stress. Indeed some marriages improve when a person with autism goes into residential care (DeMeyer and Goldberg, 1983).

Harris (1994) points out that it is not surprising that couples may experience marital distress related to their person with special needs but that there is considerable variability in the literature on how couples in this situation describe their marriage. It appears that some marriages experience a negative effect while others are strengthened by it (DeMyer, 1979a; Gath, 1978; Lonsdale, 1978). Morgan (1988) points out that the research does not allow us to draw a final conclusion on this matter.

Bristol *et al.* (1988) states that a vital ingredient of adapting to the special needs of a child with autism is the support available from a spouse. In addition Milgram and Atzil (1988) state that the mothers life satisfaction is enhanced when the father assumes his portion of the care of the person with autism. It would appear as Harris (1994) states that a woman "with primary child care responsibilities who does not feel supported by her spouse and who is confronted by a self injurious child, may find herself lonely, overwhelmed, and unable to cope with the childs exceptional needs". Beach *et al.* (1990) note the loss of social support experienced by maritally discordant couples. They note the link between the loss of such experiences as marital cohesion, acceptance, and tangible assistance and

depression in some marriages which are disharmonious. Harris (1994) points out that if a child with autism poses serious management problems this can increase the marital disharmony and each partner's despair. She notes that marital disharmony can increase when their arguments focus on decisions about what is best for the child and depression can be increased by each parents sense of failure in meeting the childs needs. Fadden *et al.* (1987) showed the "considerable strain on marital relationships" of caring for a psychiatric patient as well as a fall in family income and marked restrictions in social and leisure activities. They suggested that there should be a "service for the relatives".

The group of mothers (15) who scored particularly highly on the G.H.Q. were particularly stressed. These mothers were possibly in need of special services. Indeed it is possible that the G.H.Q. could be used as a screening instrument for mothers of persons with autism to assess levels of stress. It is possible that stressed mothers could have been helped by parent training in how better to manage their persons with autism particularly with disruptive behaviours. If they could teach their persons with autism new adaptive skills this may also reduce stress on mothers. Parents can learn new skills and have more time for family recreation because they then spend less time in "custodial" activities with their persons with autism (Harris *et al.*, 1991; Kolko, 1984; Koegel *et al.*, 1984). These approaches would clearly be less successful with chaotic disorganised families.

In addition those mothers who had persons with autism who were more stubborn and had more habits and mannerisms were more likely to be in the poor health group. This last finding suggested that characteristics of the person with autism were playing some part in mothers showing increased stress. The personality characteristics of mothers was not studied something that could have some role to play in explaining the differences between the two groups of mothers. Likewise in future it would be interesting to study personal and family histories of the mothers to see if they had a previous history of psychiatric illness or a family history of psychiatric illness. The same could apply to physical illness in the mother. It would also be interesting in the future to study "hardiness" and resilience in both groups of mothers. Indeed Gill and Harris (1991) found that "hardiness" was a good predictor of depressive symptoms among mothers of children with autism. This suggests that the non-stressed mothers ("good psychological health" less than 5 on G.H.Q.) were either resilient or "invulnerable" or had special personality resources or support which enabled them to cope with the stress or alternatively that they had some other resources to cope with the burden of the person with autism e.g. "hardiness" (Ganellen and Blaney, 1984; Kobasa, 1979) and hardy people are said to be resilient in the face of adversity because of their sense of control, commitment and challenge.

Another factor that may be relevant here is mothers perception of herself as a "successful parent of a person with autism". Hirsch (1981) conceives of social networks as personal communities and emphasizes their capability to embed a repertoire of satisfactory social identities over the life-span. If a mother could recognise herself as a "successful parent of a person with autism" this positive identification could make it easier for her to cope with the person with autism.

As discussed earlier there is evidence and it is supported by clinical experience that mothers with more financial resources can employ baby-sitters etc. so that their work and leisure activities are less interfered with.

Another finding which would surprise clinicians was that there was no statistically significant difference between the G.H.Q. scores of mothers with a person with autism and mothers of control children although it did approach significance ($p = .076$). Harris (1994) points out a similar finding that "parents of children with autism do not exhibit greater degrees of psychopathology than the population as a whole". Koegel *et al.* (1983) reports a similar finding. Nevertheless even on statistical grounds one would expect some families to bring various forms of family dysfunction and psychopathology to the additional task of rearing a child with autism. Harris (1994) points out that these families "do on average, report more feelings of depression, somatic complaints, and marital discomfort than their peers" but that they can be buffered by a "good social support network, family cohesion, and effective coping skills". It is worth nothing that Alloway and Bebbington (1987) are very critical of the notion of buffering.

Siblings

The impact on siblings of having a person with autism in the family was largely negative. Indeed 69% of mothers stated that their contact with their other children in the family was negatively effected because of the person with autism. Nevertheless the situation is complex with 7% of mothers stating that having a person with autism in the family improved their relationship with their other children. These findings suggest that increased attention needs to be given to the needs of siblings. This might be through sibling support groups or new interventions to specifically target the particular stresses on siblings.

It is interesting that maternal estimation of the impact of a person with autism on siblings was variable in this E.R.H.A. study ranging from 18% who stated it had no impact to 29% who said it had severe impact on siblings. When Mates (1990) examined the effects of being a sibling of a child with autism he identified little difference between his sample of siblings of children with autism and normative data. McHale *et al.* (1986) produced a similar result using self report measures. At the same time some of these children describe very positive relationships with their handicapped siblings and other describe very negative relationships with their handicapped siblings. There was clearly variability of response. The siblings had to deal with the frustration of dealing with an unresponsive handicapped sibling; demands to function as an auxiliary parent and the loss of parental attention. Sometimes the siblings were upset by the response of their peers to the handicapped person. It is possible that some of the siblings stress could be shared in a sibling support group and only 15% in this E.R.H.A. study were in such a support group. Harris (1994) points out that these problems may be aggravated if the child with autism shows severe behaviour problems which further reduces parental resources and make it difficult for siblings to bring friends home. She concludes that there is a need for research to differentiate "the adaptive from maladaptive functioning family and how we might enable the less well functioning family to improve its response to this family crises".

The sibling support groups could focus on anger the siblings may feel from having a sibling with autism. They could also discuss their resentment of the extra attention the child with autism receives. Older siblings are sometimes concerned about the genetics of autism and their feelings about it could be discussed in the group. Genetic counselling would require skilled help. They could also learn skills to help them interact with their siblings with autism (Harris *et al.*, 1991).

6.8 Competence of Person with Autism

The level of competence of these persons with autism is relevant and indeed the Index of Social Competence significantly differentiated between those mothers who showed evidence of stress and scored over five on the GHQ from those who did not. It is clear that the persons with autism were quite dependent in terms of self care skills for example 15% were completely dependent on others to look after their personal needs. Only 6% could prepare a variety of meals and 79% had no understanding of money. Only 12% could read and follow instructions.

The Index of Social Competence can be broken down into four areas in terms of ability i.e.:

(1) Additional handicaps.

(2) Communication skills.

(3) Self care skills.

(4) Community skills.

A score lower than the median in all four areas indicates low ability range. Other combinations indicate mixed ability. 93% of persons with autism studied fell into the mixed ability range.

Baron-Cohen and Bolton (1993) describe "specific problems in autism". They mention tantrums as one of these and it is of interest that on the Vineland Maladaptive Domain (Sparrow *et al.*, 1986) 49% of mothers describe tantrums as occurring usually or habitually. Baron-Cohen *et al.* (1993) also mentions self injury as a "specific problem in autism". In this E.R.H.A. study this occurred in (21%) of cases where it was a usual activity. They also pointed out that most people with autism do not show excessive aggression but that "sometimes certain kinds of aggression are seen in persons with autism i.e. "hitting or in some way hurting another person". In this E.R.H.A. study 20% were physically aggressive (usually or habitually) which may be due to the group being lower functioning.

6.9 Placement

There was a significantly positive correlation between residential status and age i.e. with increasing age persons with autism being found to be more likely to be in residential care. This maybe because families were less able to cope with their sons or daughters with autism as the parents got older and the persons with autism became bigger and stronger. There was a puzzling finding in that no relationship was found between residential status and maternal mental health. One could speculate that this was because mothers often have their persons with autism home at weekends or during holiday times. A further speculation would be the guilt and anxiety that having a person with autism can create. At a clinical level one hears parents often express fears about the future and even worry about their child being sent home from a residential unit when these fears are without foundation. Of course there is also some evidence that placing a child in residential care can save or improve a marriage (DeMyer and Goldberg, 1983).

Generally a person with autism is not put into residential care for many years after the diagnosis is made so it is possible that mothers became psychologically stressed by years of coping and never recovered after the residential care placement. While the word coping certainly makes clinical sense it is a construct that has come under considerable scrutiny. Garmezy (1990) points out that coping as a construct leaves much to be desired. He states that its limitations reside in the quality of the instruments for measuring coping, their lack of psychometric properties and the questionable assumption of transitional generalizations that can be drawn from test responses to hypothetical or even actual situations. It is possible if mothers are given rapid support and help in times of crises or when they are in a phase of reawakening of sadness, anger and grief at various times during the life cycle that these crises and feelings then do not become chronic and lead to 'burn out' of mothers and others. There is a possibility that this may have happened to mothers of persons with autism in residential care in this E.R.H.A. study because there was continuing evidence of psychological stress even after the person with autism went into residential care.

6.10 Sharing a Classroom with Children with Other Types of Non-autistic Handicaps

This was not uncommon in this E.R.H.A. study. It can work satisfactorily if the teachers are all specially trained in the management of persons with autism and have individual programmes for autistic children as described in the introduction.

6.11 Parent Staff Meeting

The 154 mothers of persons with autism meeting staff six monthly or less would appear to be meeting too infrequently particularly when one wants meaningful involvement of parents in programmes. It is interesting that in a study of caring and its burdens (Fadden *et al.*, 1987) spouses complained of "being deprived of information and advice" by professional staff. There would appear to be a considerable need for an increase in speech and language therapists since language problems are such a feature of persons with autism. Parental satisfaction with services was satisfactory. It is uncertain whether the same level of satisfaction would pertain if this was assessed anonymously.

There would appear to be a need for an increase in specific skills programmes for persons with autism since current skills inputs include 39% having independent living skills programmes and 35% having language therapy. Again persons with autism tend to have fundamental deficits in these areas.

There would also appear to be a need for increased parental involvement in Individual Education Plans since 87% only attended meetings. There should be a move to take on parents as co-therapists. The relationship between therapists and patients should be one of partnership - both working towards the same goals of improving the skills and quality of life of the person with autism.

All staff working with persons with autism should have specific training in relation to the issues relating to the features of autism as well as the special problems that persons with autism present with. This should focus on non-aversive interventions. It is critical that

they are familiar with the major deficits of autism and know that they have to give increased explanation to persons with autism, adequate warning of change of activity etc.. It is evident from clinical experience that parents feel more supported and understood when they talk to someone who is knowledgeable about autism. Staff should attend regular refresher courses.

The families with the person with autism need most of the skills and treatment methods available in psychiatry, psychology, social work, paediatrics, education and speech and language therapy.

There is also a need for long term planning for persons with autism. Long term planning has significant resource implications for service providers. In this study about half the families had not had discussions about the long term implications of autism. It is possible that plans had been considered but not fully communicated with parents. It is also possible that these discussions were forgotten by parents. Parents are naturally very concerned about the long term implications of autism. On the positive side is the fact that considerable resources are being made available for the long term residential and day care of persons with autism in the E.R.H.A. area.

6.12 Future Research

(1) There is a need for further diagnostic work into sub-typing of autism. The author also agrees with Gillberg (1995a) that future studies need to examine the whole spectrum of social interaction disorders. It might be useful also to study "'partial syndromes'" where the patient has some of the criteria for say a DSM-IV disorder or an ICD10 disorder but does not have the full criteria for a diagnosis of autism. These are often also called PDDNOS. Gillberg (1995a) suggests that patients who screen positive for one, two or three of Wing and Gould's (1979) triad of impairments would increase our understanding.

(2) There is a need for further work into the gender effects in autism.

(3) There is a need for a study in the Irish context which would be a total population study.

(4) There is a need for further study of the rates of persons with autism in the various socio-economic groupings.

(5) There is a need for further studies examining the similarities and differences between high functioning autism (HFA) and Asperger Syndrome.

(6) There is a need for a detailed longitudinal study of the effects of the diagnosis of autism on the individual members of the family at say three monthly intervals and long term. This would include an investigation of chronic sorrow. This E.R.H.A. study used a control group drawn from the normal school systems. Future control groups should use persons drawn from groups with (non-autistic) disabilities or handicaps. Guilt could also be studied using The Parenting Stress Index for younger children (Abidin, 1983).

(7) There is also a need to conduct research into the social density and types of social networks of families with a person with autism.

(8) There is a need for further study of the personal coping strategies which are most effective in ameliorating the burden of having a person with autism in the family.

(9) There is a need for further research into intervention strategies of a behavioural and cognitive behavioural type.

(10) There is a need for new intervention strategies to help the special stresses that many siblings of persons with autism experience.

(11) There is a need for further study of the benefits and deficits of integrated versus specialized education.

(12) There is also a need for further studies of aspects of service interventions that cause stress to families of persons with a person with autism.

(13) There is also a need for the study of the benefits of diagnosis at the local level versus diagnosis at central regional centres of excellence with very complex statementing procedures.

(14) There is a need for a detailed study of the knowledge of autism of personnel in all services who have one or more persons with autism in their service.

(15) There is a need for a detailed study of the availability and need for respite care of long and short term duration for persons with autism.

(16) There is a need for a psychosocial study of elderly persons with autism.

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Appendix A

Autistic Disorders Diagnostic Checklist
Lorna Wing (1987 - Personal Communication)

Screening Psychiatric (Behavioural) Manifestations

N.B. All the features listed below must be evaluated for their significance in the light of the individual's mental age.

Criteria essential for diagnosis

A.

A qualitative impairment in reciprocal social interaction as manifested, during childhood, by at least one item under 3 or more of the numbered items groups.

☐ 1. **Absence or impairment of use of eye to eye gaze, facial expression, body posture and gestures to initiate and modulate reciprocal social interaction**

☐ a Does not anticipate being held (e.g. by lifting arms, changing posture, showing eagerness in facial expression)

☐ b Does not adapt posture, cuddle in when held, may stiffen and resist when held

☐ c Does not look or smile when making a social approach

☐ d Does not use eye contact to get someone's attention. May make eye contact in brief glances only, but not for the purposes of gaining another's attention

☐ e Does make eye contact, but does so inappropriately (e.g. holds someone's face and looks closely into their eyes when wanting their attention)

☐ f Does make social approaches, but does not use variations in eye to eye gaze, etc., or vocalizations such as 'um' or 'ah' to punctuate conversations and to guide turn talking

☐ 2. **Absence or impairment of interactive play or sharing of interests**

☐ a Does not reciprocate in lap play (e.g. if mother touches and names child's nose and mouth, the child ignores, or may show some signs of pleasure, but does not reciprocate by touching mother's nose and mouth in his turn)

☐ b Does not point things out to others and use eye contact in order to share the pleasure of seeing something interesting (not to be confused with pointing to indicate the desire to obtain an object)

☐ c Does not spontaneously bring toys or other possessions to show other people to share pleasure and interest. Does not spontaneously offer others real or pretend food or drink

☐ d Self chosen play activities are solitary

☐ e Involves other children only as mechanical aids (e.g. to bring objects to add to a construction)

☐ f Directs other children as 'puppets' in a repetitive game. No interest in other children's suggestions

☐ g Amiably accepts passive role in other children's play (e.g. as baby in a game of 'mothers and fathers'), but makes little or no contribution

☐ h Engages with one other specific person who has the same circumscribed interest (e.g. train or aeroplane spotting, playing chess). The social interaction is dominated by the one theme

☐ 3. **Abnormalities of greeting behaviour**

☐ a Does not rush to greet parent after a period of separation

☐ b Does not spontaneously wave to greet or when saying goodbye

☐ c Ignores visitors to the house, classroom etc. (not just because absorbed in some activity)

☐ d Says 'hello' or some stereotyped phrase but only when prompted, or because of previous training

☐ e Makes approaches indiscriminately and inappropriately to familiar people and strangers alike

☐ 4. **Abnormalities in seeking comfort**

☐ a Never seeks comfort. Appears to ignore pain, heat, or cold

☐ b Seeks comfort, but only in a mechanical way (e.g. sits on human lap as if the person were a chair)

☐ c Shows distress if hurt, but does not come for comfort

☐ d Approaches others if hurt, but in a stereotyped way, and does not seek or respond to comforting (e.g. always demands "put plaster on it" regardless of cause of pain)

☐ e Approaches others, intrudes upon them, may cling tightly to them regardless of the needs and feelings of the person approached. May superficially appear to be seeking comfort or affection, but behaviour has a bizarre, repetitive quality

☐ 5. **Abnormalities in giving comfort to others**

☐ a Ignores existence of and walks through and over other people, regardless of their feelings. Is unaware of others' 'personal space'

☐ b Indifferent to others' pain or distress or may laugh at others' distress (e.g. if someone falls over or is scolded)

☐ c Is distressed by injury or illness in another person, but only because of change of appearance or routine. Does not offer comfort or sympathy

☐ d No intuitive awareness of others' pain or distress, but has some understanding on an intellectual level if problem is explained. May then try to offer comfort and sympathy, but may do this in a naive and inappropriate manner

☐ 6. **Impairment of imitation**

☐ a No spontaneous imitation of others' actions (though may be taught by having limbs moved for him/her)

☐ b Automatic, mechanical imitation of others' actions without real appreciation of the meaning, sometimes amounting to echopraxia equivalent to echolalia in speech

☐ c May imitate simple movements, but fails to engage in imitative make-believe play (e.g. does not pretend to be mother or father, teacher, doctor or nurse)

☐ d Does imitate actions of one person, animal or objet (e.g. a character seen on television, a horse, a train, a robot), but does this repetitively in a stereotyped fashion and is difficult to divert from this activity

☐ e Does try to imitate other people's actions, and is aware of necessity for correct social behaviour, but gets details wrong in a naive, even bizarre fashion.

(May be able to learn a sequence of actions, e.g. for a stage performance but only if taught each step in detail)

☐ 7. **Impairment of ability to make friendships (mutual sharing of interests and emotions)**

☐ a No peer friendships despite ample opportunities

☐ b Poor relationships with peers - other children tend to tease and bully

☐ c Wants friends but has poor grasp of the concept of friendship. May refer to all acquaintances, however slight as 'friends'

☐ d Has one 'friend', but has a limited, passive role in the partnership

☐ e Has a friend with the same circumscribed interest - talk 'at' each other mainly concerning this interest

☐ 8. **Impairment of development of social aspects of pretend play**

☐ a Fails to 'animate' toy animals and dolls or objects (e.g. Does not show tender care of and feed toy animals or dolls, or walk them along, make noises or talk in the animal's or doll's voices)

☐ b Does appear to 'animate' one or a few toys or other objects, but does so in a limited repetitive way and continues with the same activity for long periods. 'Play' does not become more elaborate with time

☐ c Invents a fantasy person or people, even an entire imaginary world, but the fantasy activities are concentrated on one or a few limited themes and are repetitive in quality (e.g. invents a fantasy family of people, but is concerned solely with talking about the details of the family tree - who is related to whom, and how - all of which are remembered with complete precision)

☐ 9. **Impairment of awareness of social rules**

☐ a Lack of awareness of need for personal modesty (e.g. will remove clothing or appear naked in any company, in complete innocence)

☐ b Lack of awareness of psychological barriers (e.g. invades other people's 'personal space'; walks behind counters in shops; enters other people's houses to 'collect' a particular object)

☐ c Lack of awareness of social taboos in conversation (e.g. makes naive, embarrassing personal remarks in public; talks about delicate subjects in a loud voice in company; asks strangers inappropriate, embarrassing questions)

☐ d Lack of awareness of correct behaviour in public (e.g. screams in public; removes objects from shelves in shops; sits down in puddles in middle of road)

B.

A qualitative impairment in communication, language (non-verbal) and symbolic development as manifested, during childhood, by either item 1b, or at least one item under 3 or more of the numbered item-groups.

☐ 1. **Impairment of use of language for communication**

☐ a In the pre-verbal stages of development, no meaningful intoned vocalizations, or communicative babbling, plus failure to compensate by alternative methods of communication such as facial expression and simple gestures

☐ b At stage when speech should be present, has no spoken language (often with a history as in a. above), and failure to compensate such as gesture and mime (apart from pulling others' hands or arms in a mechanical way)

☐ c Has speech, but neither initiates nor sustains a conversation with others

☐ d Makes approaches to others, but content of speech is one-sided, repetitive, without appropriate conversational turn-taking

☐ 2. **Impairment of comprehension of language**

☐ a No response to communication of others, (e.g. does not respond to own name)

☐ b Responds to communication of simple instructions, but only in a familiar context; actions due to learned habits rather than understanding of words

☐ c Responds to single words or phrases out of context, rather than the meaning of a whole statement (e.g. mother, while doing dishes, says "I've torn my rubber glove, get me another pair of gloves please". Child goes out of kitchen and returns with a pair of woollen gloves)

☐ d Understands a wide range of words and grammatical constructions, but has marked tendency to interpret information in a literal way, failing to take the

context into account, leading to naive mistakes (e.g. Mother, making a cake, says to a 15 year old autistic son "I need some cloves. Take some money from my purse and buy me some". Boy mishears, but asks no questions and returns some hours later with bag full of teenage girl's clothes)

☐ 3. **Impairment of use of speech (if present)**

☐ a Stereotyped and repetitive use of speech; immediate echolalia and/or repetition of phrases in a mechanical way. (The latter can vary from a vocabulary of a few words only used repetitively without meaning, to television commercials, or even whole conversations repeated in the tones and accents of the original speakers). Such stereotyped phrases may also be used to obtain simple needs

☐ b Problems with words that change in meaning with the context (pronouns, prepositions, words relating to time etc.). Most obviously shown in reversal of pronouns (e.g. "you want cookie")

☐ c Idiosyncratic use of words or phrases; these may be incorrect, concrete, literal, inverted, or actual neologisms (e.g. "earring plugs" for "ear-phones"; "shake-milk" for "milk-shake"; "go on green ridings" for go on the swing in the park"; "cushion" for apple puree)

☐ d Grammatical speech and large vocabulary, but use of speech long-winded, pedantic, lacking in colloquialisms, repetitive (e.g. "I wish to thank you for the hospitality you have extended to me this afternoon" instead of "thanks for the cup of tea")

☐ 4. Abnormalities in pitch, stress, rate, rhythm, volume or intonation of speech (e.g. speech monotonous, voice inappropriately high or low pitched, statements always have a questioning melody regardless of content)

☐ 5. **Impairment of symbolic development as shown in imaginative activities (N.B. evaluate behaviour in light of language comprehension age)**

☐ a No appropriate use of miniature objects, despite language comprehension age of 2 years or above (e.g. handles toys only to obtain simple sensory stimuli, does not lay toy tea table with toy crockery, does not imitate car noises and pretend to drive toy car)

☐ b Shows appropriate use of miniature objects when presented in test situation, but does so in a limited mechanical fashion without elaboration of pretence and does not choose and play with such toys spontaneously

☐ c Uses some toys spontaneously in an appropriate way, but play is repetitive and does not include the use of one object to represent another of a quite different kind (e.g. a banana to represent a telephone)

☐ d Has representational play, which may be elaborate (e.g. using wooden blocks to build a complex network of roads and bridges) but this is limited to the one theme and is markedly repetitive

C.

A restricted repetitive repertoire of behaviour when left to choose own activities, as manifested by one or more of the following items under any of the item-groups.

☐ 1. **Stereotyped repetitive postures or bodily movements**

☐ a Tends to stay in one position with little or no spontaneous activity (e.g. sits with legs tucked up and head bowed)

☐ b Moves around aimlessly (e.g. wanders, or runs or makes rapid darting movements, or paces to and fro)

☐ c Simple repetitive bodily movements (e.g. rocking, teeth grinding, tapping parts of own body)

☐ d More complex repetitive movements (e.g. hand clapping, twisting or flicking, complex whole body movements)

☐ 2. **Stereotyped repetitive activities related to bodily functions or sensations**

☐ a Smearing or other manipulation of saliva or excreta

☐ b Searches for and swallows inedible objects (e.g. cigarette ends, small pieces of metal, paper)

☐ c Repetitive self injury (e.g. head banging, eye poking, hand biting, self induced vomiting)

☐ d Preoccupation with visual, auditory, olfactory or tactile sensations (e.g. looks through fingers at lights, fascinated by watching things spin, listens to sounds made by water in radiators, deliberately plays records at the wrong speed, smells objects and/or people, feels, or scratches, or taps on different surfaces)

☐ 3. **Preoccupation with objects, regardless of their function**

☐ a Unusual attachment to objects (e.g. insists on carrying round a particular object such as a belt, a toy car, a stone, an empty detergent packet; tends to be angry or distressed if object is mislaid)

☐ b 'Collects' certain kinds of objects for no apparent purpose (e.g. dead holly leaves; wrappers from one brand chocolate; small tea pots; books on a specific subject which may remain unread; toy trains; tends to notice and react if even one item is missing)

☐ c Arranges objects in straight lines or patterns - upset if arrangements are disturbed

☐ d Preoccupation with parts of objects, animals or people (e.g. fascinated by animal's fur; people's teeth; church steeples; one or two bars of music out of a complete recording)

☐ e Preoccupied with repetitive actions, involving objects (e.g. flicks pieces of string or other materials; turns light switches on and off; spins the wheels of toy cars; pours water from one vessel)

☐ f Preoccupation with specific abstract attributes of objects or people, such as colour, shape, sound, number (e.g. fascinated with anything that is yellow, or round in shape, regardless of its practical function; identifies people by their numerical attributes such as age, house number)

☐ 4. Preoccupied with maintenance of small details of the familiar environment (e.g. disproportionately upset if things broken or blemished; resists changes in arrangements of ornaments; extremely upset if given different brand of orange juice; refuses to wear new shoes or other new clothes)

☐ 5. Preoccupied with the maintenance of certain familiar routines (e.g. upset if different route taken to a familiar place; insists on following a complicated bedtime ritual before going to sleep; insists that cutlery, crockery, etc., must be placed on the table in precisely the same order for each meal; eats only one or few types of food; always stands up and turns round three times before starting next course at each meal)

☐ 6. **Restricted and repetitive patterns of interests of a verbal or intellectual kind**

☐ a Asks the same questions repeatedly, regardless of the replies received (e.g. How old are you? What colour is your car? Where do you live?) or talks repetitively on one or two themes - regardless of suggestions from other children

☐ b Acts the role of an object, animal, fictional character or real person in a repetitive stereotyped way regardless of suggestions from other children

☐ c Preoccupied with special interests dependent on good rote memory, ability to calculate, or musical ability (e.g. time tables; routes to places; calendars; arithmetical calculations; computers; games depending on numbers; the music of a specific composer)

☐ d Preoccupied with particular subjects; tends to amass facts but usually lacks depth of understanding (e.g. methods of transport; meteorology; genealogy of royal families; the legends of King Arthur; military uniforms; specific imaginary or real people. The subjects may be lurid or frightening, such as details of murders or monsters from outer space)

☐ 7. Life style is restricted, empty, routine bound. Has virtually no spontaneous activities apart from those related to the daily routine.

Appendix B

Services Questionnaire

General Information:

Name/ Reference No. of client: _____

Date of birth: _____

Name of Centre/ School: _____

Number of clients attending service: _____

Age range of clients: _____

Ability range: _____

Day service ☐ Residential ☐

Both ☐ Domiciliary service ☐

1. Does client have a written individual plan which specifies strengths/ weaknesses, specific learning needs, specific programme goals.

   Yes: ☐ No: ☐

2. Are parents involved in the formulation and review of the client's IEP?

   Yes: ☐ No: ☐

What is the nature of their involvement?

_____

_____

_____

_____

3. How often is client's progress/ IEP reviewed formally by multi-disciplinary team and parents?

_____

_____

_____

_____

4. How often do parents meet with staff specifically involved in carrying out the client's programmes?

_____

_____

_____

_____

5. Are parents encouraged to carry out programme goals within the home?

   Yes: ☐ No: ☐

6. How many other individuals are there in the client's group when educational programmes are being carried out? _____

7. What is the average staff-pupil ratio during the client's educational programmes?

_____

8. Does the client receive regular 1:1 instruction or support? If yes, please specify frequency and duration.

Yes: ☐ No: ☐

9. Does the client receive educational programmes along with other individuals who have:

i. Normal intelligence ☐
ii. Mental handicap - specify degree ☐
iii. Autism and related disorders ☐
iv. Autism and related disorders ☐
v. Autism ☐
vi. Mixed handicaps ☐

10. For how many hours each day is client involved in educational programmes? _____

11. What areas of learning do client's educational programmes focus on? *Tick relevant areas.*

a. Cognitive skills ☐
b. Play skills ☐
c. Language skills ☐

d. Self help, social skills ☐
e. Interactional -relationship skills ☐
f. Independent living skills e.g. domestic, travel, shopping, ☐
g. Music therapy, ☐
h. P.E., gym ☐
i. Swimming ☐
j. Horse riding, ☐
k. Use of community facilities, shops, restaurants ☐
l. Other ☐

12. Which of the following personnel does _____ have access to? Specify frequency of contact, e.g. daily, weekly, monthly, 2 / year, etc.

Frequency

a. Physiotherapist ☐
b. Speech therapist ☐
c. Psychologist ☐
d. Social worker ☐
e. Paediatrician ☐
f. Psychiatrist ☐
g. Other - specify. _____ ☐

13. Is there a formal policy and procedure for admission to and transfer from service

	Yes	No
a. Home to school	☐	☐

b. School to adult service ☐ ☐

c. Day service to residential service ☐ ☐

14. Is there a long term service plan for the client?

Yes: ☐ No: ☐

15. Has the label/term 'autism' been used by staff when discussing the client's needs with parents.

Yes: ☐ No: ☐

16. Are the parents aware of the client's specific needs/ difficulties which are related to his/ her autistic disorder as opposed to any other handicapping condition, e.g. mental handicap, hearing impairment.

Yes: ☐ No: ☐

17. Have the long term implications of the client's autistic disorder been discussed with the parents?

Yes: ☐ No: ☐

18. Have the family members received informtion on autism form the service providing agency?

Yes: ☐ No: ☐

19. Do family members have access to individual counselling, if necessary, to assist them in accepting the client's autistic disorder?

Yes: ☐ No: ☐

20. Are parents involved in or encouraged to take part in a parent support group for families with a member who has autism?

Yes: ☐ No: ☐

21. Are siblings of clients involved in a sibling support group?

Yes: ☐ No: ☐

22. What forms of respite care are available to the family, for the client? Tick as appropriate and specify frequency and duration.

		Duration	*Frequency*
a.	Planned relief breaks		
b.	Crisis placement		
c.	Holiday project/ play scheme (during periods when day service is closed)		

Specify type of scheme, i.e.

Day ☐ Residential ☐ Both ☐

		Duration	*Frequency*
d.	Home sharing placements		
e.	In home support, e.g. babysitting, specify		

23. Have staff undergone specific training in the area of autism.

Please specify:

1. At undergraduate level. ☐
2. At postgraduate level. ☐
3. Occasional in-service course/ seminar ☐
4. Placement in "autistic" service. ☐
5. Other - specify. _____ ☐

24. How suitable is client's current placement in meeting his/her needs. Please rate according to 5 point scale bolow:

1 = very unsatisfactory

2 = unsatisfactory

3 = satisfactory

4 = good

5 = very good

Current placement rating: _____

25. Please identify any significant needs which are not being met in client's current placement?

_____

_____

_____

_____

Appendix C

The Parent's Qualitative Questionnaire

DIAGNOSIS:

Have you ever received a diagnosis explaining your child's special need?

_____

_____

_____

_____

How was the diagnosis explained to you ? _____

_____

_____

How old was your child when the diagnosis was made? _____

_____

_____

How did you initially feel about the diagnosis? _____

_____

_____

_____

How do you feel now about the diagnosis? _____

_____

_____

At what stage in your child's life did you find it most difficult to cope with your child's disability? (i.e. when child was very young, starting school, leaving school, etc.)

_____

_____

Would support from a service have helped you to cope with these difficulties?

_____

_____

Does your son/daughter receive a *Day Service*? _____

Where? _____

Does your son/daughter receive a *Residential Service*? _____

Where? _____ _____

How satisfied are you with the services your child is presently receiving?

_____

_____

_____

What recommendations would you have to improve these services?

_____

_____

_____

Do you feel that services should be provided by a voluntary *or* statutory agency?

_____

Why? _____

_____

What do you consider to be the most difficult aspect of having a child with a disability in the family?

_____

_____

_____

_____

_____

Do you think that your child's special needs has had an impact on his/her siblings?

Severe Impact *Moderate Impact* *Slight Impact* *No Impact*

_____

_____

Do you think that _____'s special needs have prohibited the amount/quality of contact you have with your other children?

Severely Prohibited *Moderately Prohibited* *Slightly Prohibited* *Does not Prohibit* *Improved Relationship*

_____ _____ _____ _____ _____

Are any of _____'s *siblings* involved in helping to care for other members of the family?

_____

Describe the nature of their involvement: _____

_____

_____

_____

_____

Do you think that _____ is overprotected?

_____

_____

_____

_____

Severely *Moderately* *Slightly* *No* *Don't Know*

_____ _____ _____ _____ _____

Are _____ 's brothers and sisters concerned about genetic aspects of autism?

Severe Worry	*Moderate Worry*	*Slight Worry*	*No Concern*	*Don't Know*

_____

_____

_____

_____

* *

How often does your son/daughter return home for visits/holidays?

_____

_____

_____

_____

What are your feelings about his/her visit? (e.g. happy, anxious, dread, etc.)

_____

_____

_____

Always	*Often*	*Occasionally*	*Seldom*	*Never*
5	*4*	*3*	*2*	*1*

How often do you feel _____ ?

_____. Emotionally drained form caring for _____?

_____. Feel used up at the end of the day.

_____. Feel fatigued to get up in the morning and face the day.

_____. Feel burned out from caring for _____?

_____. Feel frustrated from caring for _____?

_____. Feel very energetic?

What are your ambitions/wishes for your child?

_____

_____

_____

_____

What are your immediate priorities?

_____

_____

_____

_____

_____

Any other comments?: _____

_____

_____

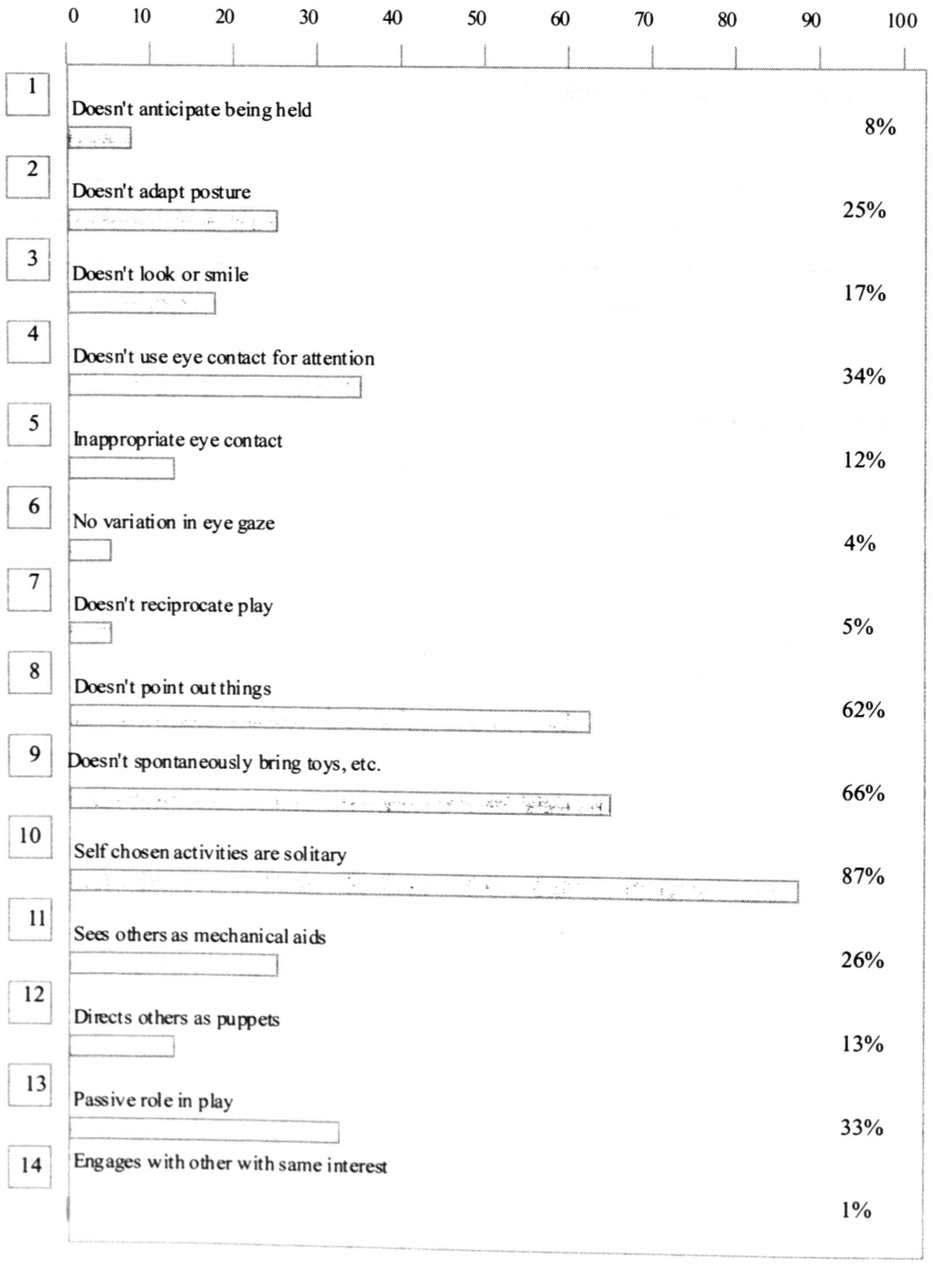
_____

_____

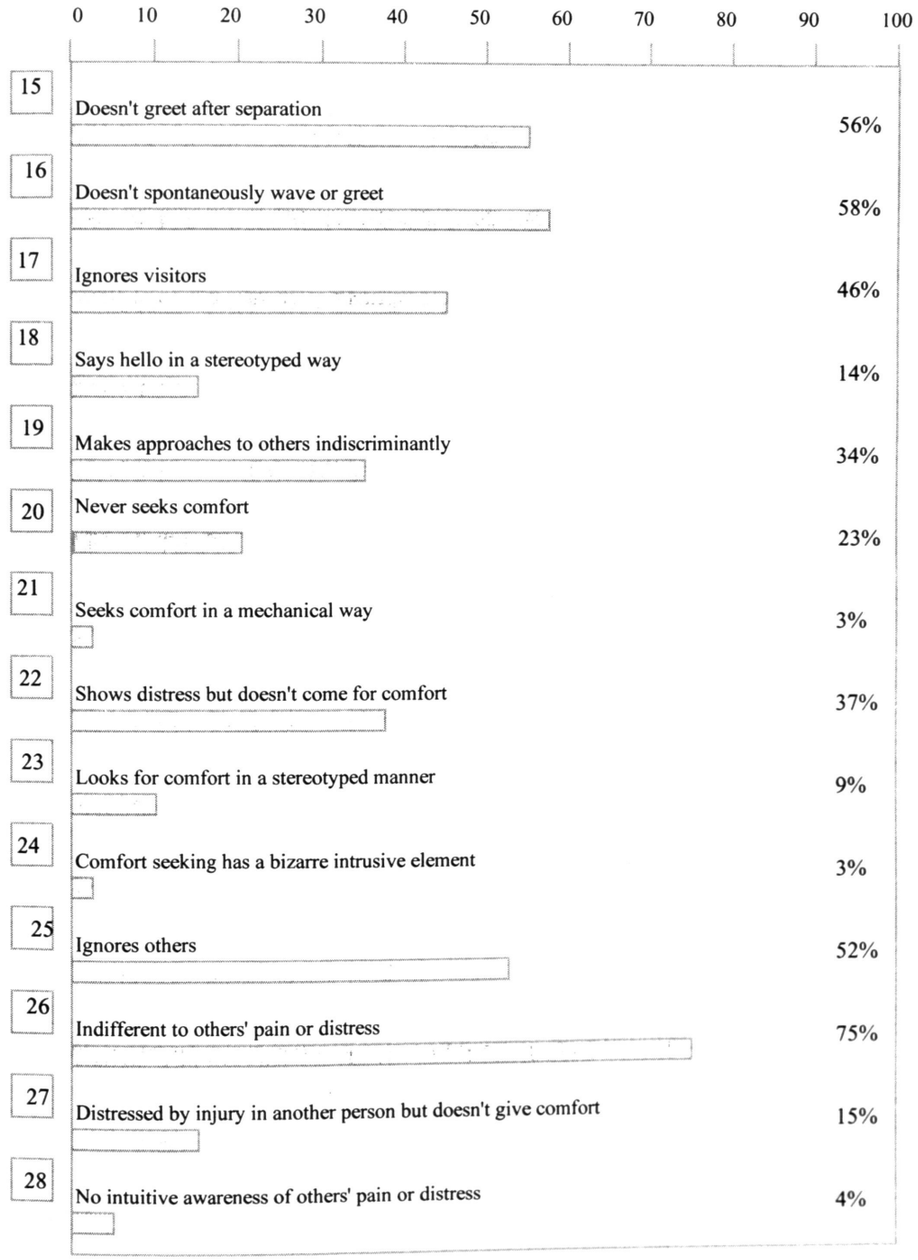
Appendix D

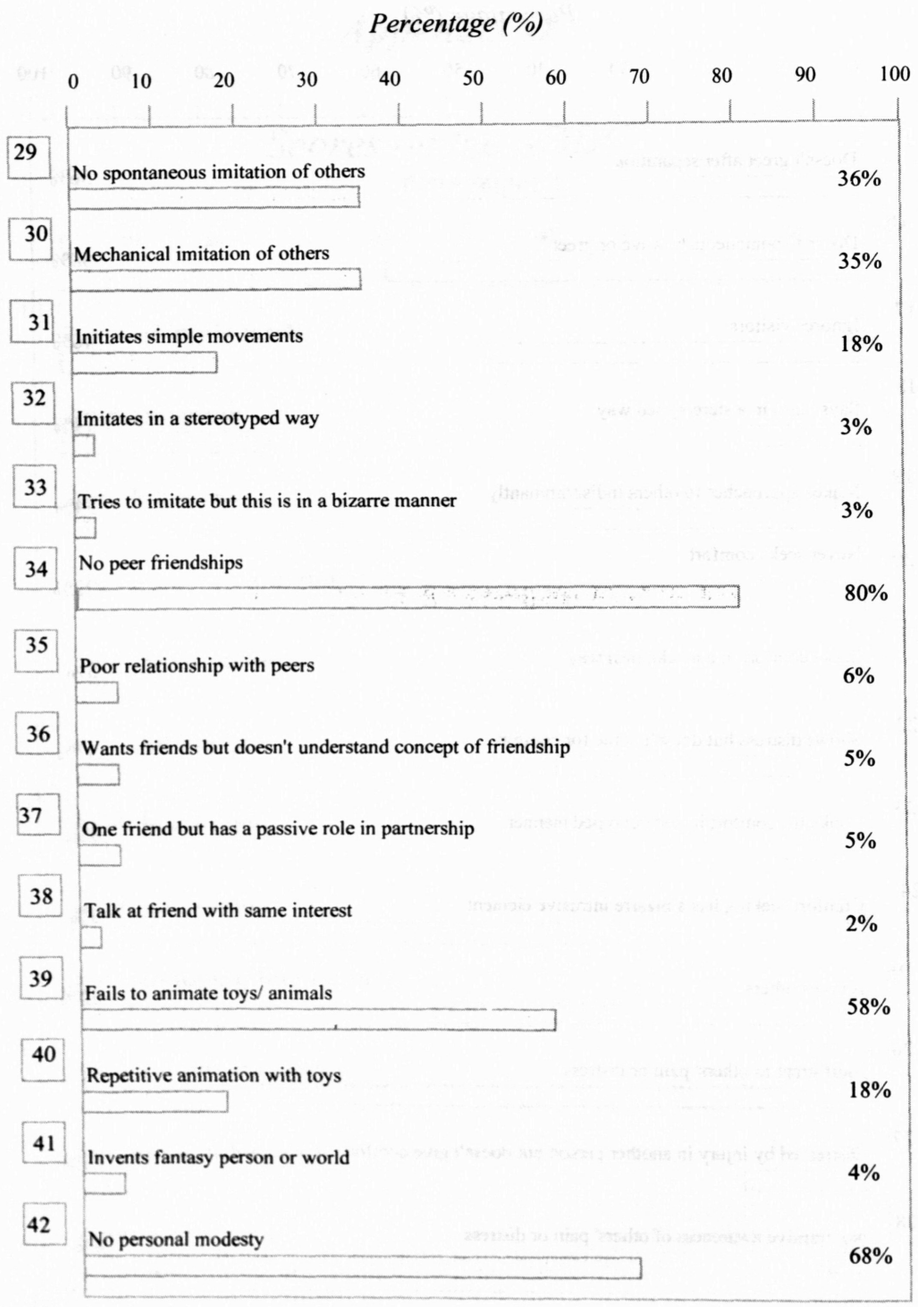
Scores on the ADDC

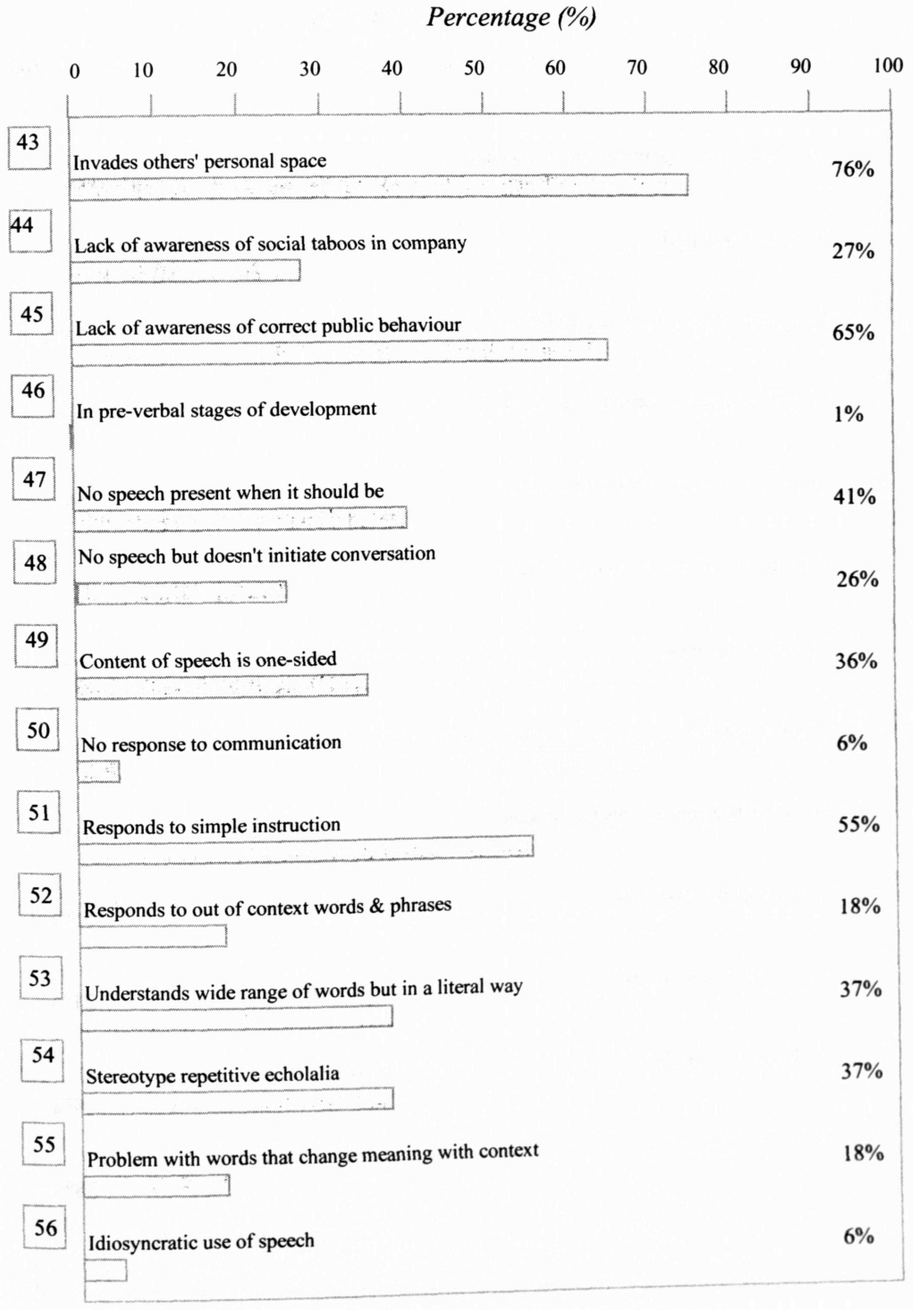
Percentage (%)

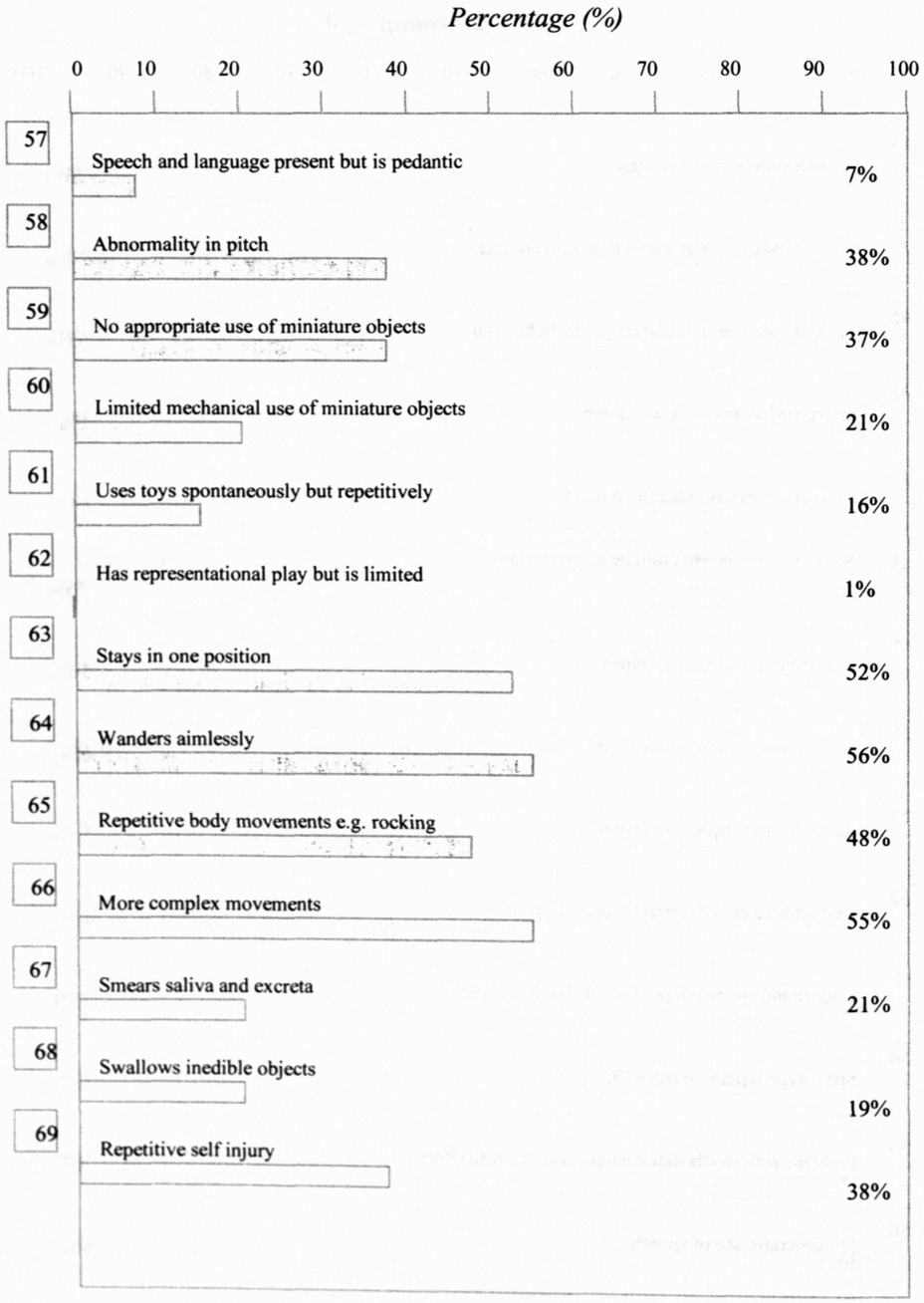


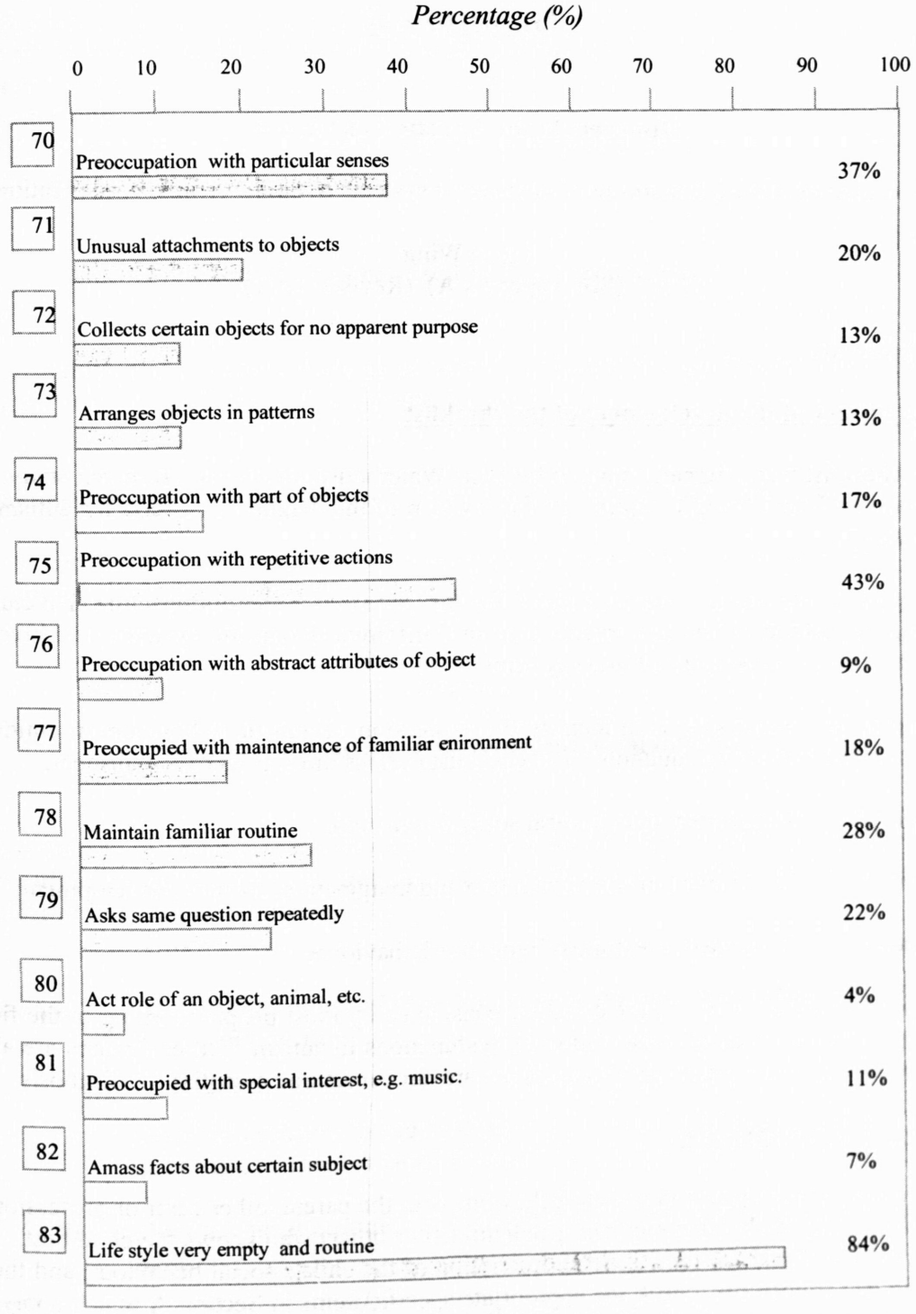
Percentage (%)




Percentage (%)
0 10 20 30 40 50 60 70 80 90 100
29 No spontaneous imitation of others 36%
30 Mechanical imitation of others 35%
31 Initiates simple movements 18%
32 Imitates in a stereotyped way 3%
33 Tries to imitate but this is in a bizarre manner 3%
34 No peer friendships 80%
35 Poor relationship with peers 6%
36 Wants friends but doesn't understand concept of friendship 5%
37 One friend but has a passive role in partnership 5%
38 Talk at friend with same interest 2%
39 Fails to animate toys/ animals 58%
40 Repetitive animation with toys 18%
41 Invents fantasy person or world 4%
42 No personal modesty 68%


Percentage (%)
0 10 20 30 40 50 60 70 80 90 100
43 Invades others' personal space 76%
44 Lack of awareness of social taboos in company 27%
45 Lack of awareness of correct public behaviour 65%
46 In pre-verbal stages of development 1%
47 No speech present when it should be 41%
48 No speech but doesn't initiate conversation 26%
49 Content of speech is one-sided 36%
50 No response to communication 6%
51 Responds to simple instruction 55%
52 Responds to out of context words & phrases 18%
53 Understands wide range of words but in a literal way 37%
54 Stereotype repetitive echolalia 37%
55 Problem with words that change meaning with context 18%
56 Idiosyncratic use of speech 6%


Percentage (%)
0 10 20 30 40 50 60 70 80 90 100
57 Speech and language present but is pedantic 7%
58 Abnormality in pitch 38%
59 No appropriate use of miniature objects 37%
60 Limited mechanical use of miniature objects 21%
61 Uses toys spontaneously but repetitively 16%
62 Has representational play but is limited 1%
63 Stays in one position 52%
64 Wanders aimlessly 56%
65 Repetitive body movements e.g. rocking 48%
66 More complex movements 55%
67 Smears saliva and excreta 21%
68 Swallows inedible objects 19%
69 Repetitive self injury 38%


Percentage (%)
0 10 20 30 40 50 60 70 80 90 100
70 Preoccupation with particular senses 37%
71 Unusual attachments to objects 20%
72 Collects certain objects for no apparent purpose 13%
73 Arranges objects in patterns 13%
74 Preoccupation with part of objects 17%
75 Preoccupation with repetitive actions 43%
76 Preoccupation with abstract attributes of object 9%
77 Preoccupied with maintenance of familiar enironment 18%
78 Maintain familiar routine 28%
79 Asks same question repeatedly 22%
80 Act role of an object, animal, etc. 4%
81 Preoccupied with special interest, e.g. music. 11%
82 Amass facts about certain subject 7%
83 Life style very empty and routine 84%

Appendix E

Disorders in the Autistic Continuum

Checklist of clinical features used in different systems of diagnosis and classification

Lorna Wing
1987 (See Appendix A) (Revised 1991)

Introduction

Brief history of the development of the checklist

This checklist was originally devised by Lynn Waterhouse for use in a research study. It is based on Lorna Wing's suggestions for revision of the diagnostic criteria for autism in DSM III R.

The present version is a revision made for the purpose of classifying clinical pictures shown by individuals on the criteria used in 5 different diagnostic systems (see below) thus allowing comparisons of these systems.

The goal of the checklist is to identify the expression of autistic behaviours in children from earliest infancy to adulthood. The checklist defines three areas of impairment:

Section A. Impairment in reciprocal social interaction;

Section B. Impairment in communication and imaginative, creative, development;

Section C. Restricted repertoire of repetitive behaviours.

These three areas (A, B, C) are currently considered by most people working in the field to represent the cardinal constellation of dysfunctions in autism. Other features are also common (e.g. over-sensitivity to sound) but are not considered essential for diagnosis.

How to use the checklist

Discuss the child's past and present behaviour with the parent, other carer or professional (teacher, child study team member, paediatrician or other) who knows the child best. As with the Vineland, ask for a general description of the child's social behaviour, and then, within that framework, check the appropriate specific items in Section A which apply to the child. Do the same for Sections B and C - that is, ask about communication, and then find which behaviours apply, and ask about repetitive activities, and find out which, if any, the child engages in.

Diagnostic categories

Different systems of diagnosing autism and related conditions use criteria that overlap but differ in detail. This checklist can be used to elicit the criteria for the following diagnostic systems:

DSM-III-R Draft Criteria (See Appendix J, page 359)
ICD 10, Draft Research Criteria (See Appendix J, page 364)
Kanner's syndrome (Kanner and Eisenberg, 1956)
Asperger's syndrome (Wing, 1981a)
Wing & Gould's triad of social impairments (Wing & Gould, 1979)
Kanner and Eisenberg's two criteria (1956)

Clinical Features Used In Diagnostic Systems

N.B. All the features listed below must be evaluated for their significance in the light of the individual's overall level of development.

'Impairment' is used to include absence, delay and abnormality of development.

The features described by Kanner in his papers are marked (*) in the checklist. The features described by Asperger are marked (+) in the text.

Section A

Qualitative impairment in reciprocal social interaction

The examples of features (a,b,c etc) for each item are arranged in developmental order. The earlier examples tend to be seen in younger or more handicapped children, the later in older or less handicapped people.

Item A1. Impairment of use of body language to initiate and modulate social interaction

- *a Does not anticipate being held (e.g. by lifting arms, changing posture, showing eagerness in facial expression)
- *b Does not adapt posture, cuddle in when held, may stiffen and resist when held
- *c Does not look or smile when making social approach
- *d Does not use eye contact to get someone's attention. May make eye contact in brief glances only, but not for the purpose of gaining another's attention
- +e Does make eye contact, but does so inappropriately (e.g. stares too long and hard; holds someone's face and looks closely into their eyes when wanting their attention)

- +f Does make social approaches, but does not use variations in eye to eye gaze, etc., or vocalizations such as 'um' or 'ah' to punctuate conversations and to guide turn taking.

Item A2. Impairment of greeting behaviour

- *a Does not rush to greet parent after a period of separation
- *b Does not spontaneously wave to greet or when saying goodbye
- *c Ignores visitors to the house, classroom etc. (not just because absorbed in some activity)
- d Says 'hello' or some stereotyped phrase but only when prompted, or because of previous training
- +e Makes approaches indiscriminately and inappropriately to familiar people and strangers alike.

Item A3. Impairment of seeking comfort

- *a Never seeks comfort. Appears to ignore pain, heat, or cold
- *b Seeks comfort, but only in a mechanical way (e.g. sits on human lap as if the person were a chair)
- *c Shows distress if hurt, but does not come for comfort
- *d Approaches others if hurt, but in a stereotyped way, and does not seek or respond to comforting (e.g. always demands "put plaster on it" regardless of cause of pain)
- e Approaches others, intrudes upon them, may cling tightly to them regardless of the needs and feelings of the person approached. May superficially appear to be seeking comfort or affection, but behaviour has a bizarre, repetitive quality.

Item A4. Impairment of giving comfort, and awareness and sharing of feelings of others

- *a Ignores existence of and walks through and over other people, regardless of their feelings. Is unaware of others' 'personal space'

- *b Indifferent to others' pain or distress or may laugh at others' distress (e.g. if someone falls over or is scolded)
- +c Is distressed by injury or illness in another person, but only because of change of appearance or routine. Does not offer comfort or sympathy
- +d No intuitive sympathy with others' pain or distress, but has some understanding on an intellectual level if problem is explained. May then try to offer comfort and sympathy, but may do this in a naive and inappropriate manner
- *+e Lack of vicarious pleasure in other people's happiness and/or lack of seeking to share happiness or pleasure with others.

Item A5. Impairment of ability to make friendships and to share interests and emotions

- *+a No peer friendships despite ample opportunities
- +b Poor relationships with peers - other children tend to tease and bully
- +c Wants friends but has poor grasp of the concept of friendships. May refer to all acquaintances, however slight, as 'friends'
- +d Has one 'friend', but has a limited, passive role in the partnership
- +e Has a friend with the same circumscribed interest - talk 'at' each other mainly concerning this interest. Apart from this, no sharing of a variety of interests.

Item A6. Impairment of awareness of social rules

- *a Lack of awareness of need for personal modesty (e.g. will remove clothing or appear naked in any company, in complete innocence)
- *b Lack of awareness of psychological barriers (e.g. invades other people's 'personal space'; walks behind counters in shops; enters other people's houses to 'collect' a particular object)
- c Lack of awareness of correct behaviour in public (e.g. screams in public; removes objects from shelves in shops; sits down in puddles in middle of road)

- +d Lack of awareness of social taboos in conversation (e.g. makes naive, embarrassing personal remarks in public; talks about delicate subjects in a loud voice in company; asks strangers inappropriate, embarrassing questions)

- *+e Lack of awareness of and/or inappropriate response to other people's emotions

Item A7. Impairment of joint referencing and interactive play

- *a Does not reciprocate in lap play (e.g. if mother touches and names child's nose and mouth, the child ignores, or may show some signs of pleasure, but does not reciprocate by touching mother's nose and mouth in his turn)

- *b Does not point things out to others and use eye contact in order to share the pleasure of seeing something interesting (not to be confused with pointing to indicate the desire to obtain an object)

- *c Does not spontaneously bring toys or other possessions to show other people to share pleasure and interest. Does not spontaneously offer others pretend food or drink

- *d Self chosen play activities are solitary

- *e Involves other children only as mechanical aids (e.g. to bring objects to add to a construction)

- *f Directs other children as puppets' in a repetitive game. No interest in other children's suggestions

- +g Amiably accepts passive role in other children's play (e.g. as baby in a game of 'mothers and fathers'), but makes little or no contribution

- +h Engages with one other specific person who has the same circumscribed interest (e.g. train or aeroplane spotting, playing chess). The social interaction is dominated by the one theme.

Item A8. Impairment of imitation

- *a No spontaneous imitation of others' actions (though may be taught by having limbs moved for him/her)

- *b Automatic, mechanical imitation of others' actions without real

appreciation of the meaning, sometimes amounting to echopraxia equivalent to echolalia in speech

- *c May imitate simple movements, but fails to engage in imitative make believe play (e.g. does not pretend to be mother or father, teacher, doctor or nurse)

- d Does imitate actions, of one person, animal or object (e.g. a character seen on television, a horse, a train, a robot), but does this repetitively in a stereotyped fashion and is difficult to divert from this activity

- e Does try to imitate other people's actions, and is aware of necessity for correct social behaviour, but gets details wrong in a naive, even bizarre fashion. (May be able to learn a sequence of actions, e.g. for a stage performance but only if taught each step in detail).

Item A9. Impairment of social aspects of pretend play

- *a Fails to animate toy animals and dolls or objects (e.g. Does not show tender care of and feed toy animals or dolls, or walk them along, make noises or talk in the animal's or doll's voices)

- +b Does appear to 'animate' one or a few toys or other objects, but does so in a limited repetitive way and continues with the same activity for long periods. 'Play' does not become more elaborate with time

- +c Invents a fantasy person or people, even an entire imaginary world, but the fantasy activities are concentrated on one or a few limited themes and are repetitive in quality (e.g. invents a fantasy family of people, but is concerned solely with talking about the details of the family tree - who is related to whom, and how - all of which are remembered with complete precision).

Section B

Qualitative impairments in communication and imagination

The examples for each item are arranged in developmental order as for Section A.

Item B1. Impairment of use of language for communication

- *a In the pre-verbal stages of development, no meaningful intoned vocalizations, or communicative babbling, plus failure to compensate by alternative methods of communication such as facial expression and

simple gestures

- *b At stage when speech should be present, has no spoken language (often with a history as in a) above), and fails to compensate with gesture and mime, apart from pulling others' hands or arms in a mechanical way, or simple pointing

- *c Has speech, but neither initiates nor sustains a conversation with others

- +d makes approaches to others, but content of speech is one - sided, repetitive, without appropriate conversational turn-taking.

Item B2. Impairment of comprehension of language

- *a No response to communication from others, (e.g. does not respond to own name)

- *b Responds to communication of simple instructions, but only in a familiar context; actions due to learned habits rather than to understanding of words

- *c Responds to single words or phrases out of context, rather than the meaning of a whole statement (e.g. mother, while doing dishes, says "I've torn my glove, would you get me another pair please". Child goes out of kitchen and returns with a pair of woollen gloves)

- +d Understands a wide range of words and grammatical constructions, but has marked tendency to interpret information in a literal way, failing to take the context into account, leading to naive mistakes (e.g. Mother, making a cake, says to a 15 year old autistic son "I need some cloves. Take some money from my purse and buy me some". Boy mishears, but asks no questions and returns some hours later with bag full of teen-age girl's clothes).

Item B3. Impairment of use of speech (if present)

- *a Stereotyped and repetitive use of speech, immediate echolalia and/or repetition of phrases in a mechanical way. The latter can vary from a vocabulary of a few words only used repetitively without meaning, to television commercials or even whole conversations repeated in the tones and accents of the original speakers. Such stereotyped phrases may also be used to obtain simple needs.

- *b Problems with words that change in meaning with the context (pronouns, prepositions, words relating to time etc.). Most obviously shown in reversal of pronouns (e.g. "you want cookie")

- *c Idiosyncratic use of words or phrases. These may be incorrect, concrete, literal, inverted, or actual neologisms (e.g. "earring plugs" for "ear-phones"; "shake - milk" for "milk shake"; "go on green ridings" for "go on the swing in the park"; "cashin" for apple puree)

- +d Grammatical speech and large vocabulary but use of speech long - winded, pedantic, lacking in colloquialisms, repetitive (e.g. "I wish to thank you for the hospitality you have extended to me this afternoon" instead of "thanks for the cup of tea").

Item B4. Impairment of prosody

- *+a Abnormalities in pitch, stress, rate, rhythm, volume or intonation of speech (e.g. speech monotonous, voice inappropriately high or low pitched; statements always have a questioning melody regardless of content).

Item B5. Impairment of non-verbal communication

- +a Little or no use of non-verbal communication (body language) (e.g. gesture, facial expression, body posture and movement, degree of nearness to others etc.) to accompany speech, to substitute for speech or to express feelings towards others

- +b Does use non-verbal communication but in an exaggerated, inappropriate way that looks odd.

Item B6. Impairment of symbolic development as shown in imaginative activities

(Evaluate behaviour in light of language comprehension age)

- *a No appropriate use of miniature objects, despite language comprehension age of 2 years or above. (e.g. handles toys only to obtain simple sensory stimuli, does not lay toy tea table with toy crockery, does not imitate car noises and pretend to drive toy car)

- *b Shows appropriate use of miniature objects when presented in test situation, but does so in a limited mechanical fashion without elaboration of pretence and does not choose to play with toys spontaneously

- *c Uses some toys spontaneously in an appropriate way, but play is repetitive and does not include the use of one object to represent another of a quite different kind (e.g. a banana to represent a telephone)

- d Has representational play, which may be elaborate (e.g. using wooden blocks to build a complex network of roads and bridges) but this is limited to the one theme and is markedly repetitive.

Section C

Restricted, repetitive pattern of self-chosen behaviour

The examples for each item are arranged in developmental order, as for Section A.

Item C1. Stereotyped, repetitive postures or bodily movements

- a Tends to stay in one position with little or no spontaneous activity (e.g. sits with legs tucked up and head bowed)

- b Moves around aimlessly (e.g. wanders; runs; makes rapid darting movements; paces to and fro)

- c Simple repetitive bodily movements (e.g. rocking; teeth grinding; tapping parts of own body)

- *d More complex repetitive movements (e.g. hand and finger twisting or flicking; complex whole body movements).

Item C2. Stereotyped repetitive activities related to bodily functions or sensations

- a Smearing or other manipulation of saliva or excreta

- b Searches for and swallows inedible objects (e.g. cigarette ends, small pieces of metal; paper)

- c Repetitive self injury (e.g. head banging; eye poking; hand biting; self induced vomiting)

- *d Preoccupation with visual, auditory, olfactory or tactile sensations (e.g. looks through fingers at lights; fascinated by watching things spin; listens to sounds made by water in radiators; deliberately plays records at the wrong speed; smells objects and/or people; feels, or scratches or taps on different surfaces).

Item C3. Preoccupation with objects, regardless of their function

- *a Unusual attachment to objects (e.g. insists on carrying round a particular object such as a belt; a toy car; a stone; an empty detergent packet)

- *b 'Collects' certain kinds of objects for no apparent purpose (e.g. dead holly leaves; wrappers from one brand chocolates; small tea pots; books on a specific subject which may remain unread toy trains). Tends to notice and react if even one item is missing

- *c Arranges objects in straight lines or patterns - may be upset if arrangements are disturbed

- *d Preoccupation with parts of objects, animals or people (e.g. fascinated by animal's fur; people's teeth; church steeples; one or two bars of music out of a complete recording; the smell of objects; the feel of the surface; the noise objects make when shaken, tapped, thrown or if wheels are spun etc.)

- *e Preoccupied with repetitive actions, involving objects (e.g. flicks pieces of string or other materials; turns light switches on and off; spins the wheels of toy cars; pours water from one vessel to another)

- *f Preoccupation with specific abstract attributes of objects or people, such as colour, shape, sound, number (e.g. fascinated with anything that is yellow, or round in shape, regardless of its practical function; identified people by their numerical attributes such as age, house number).

Item C4. Maintenance of sameness of environment

- *a Preoccupied with the maintenance of small, often trivial aspects of the environment (e.g. disproportionately upset if things are broken or blemished; resists changes in arrangements of ornaments; upset if given a different brand of a particular food or drink; refuses to wear new shoes or

other new clothes). For some, the maintenance of sameness is shown by stubborn determination not to accept change and ingenious ways of returning to the preferred patterns, but without overt distress or a temper tantrum. The rating should be made on the evidence that the person strongly prefers that sameness be maintained as in the above examples.

Items C5. Maintenance of sameness of routines

- *a Preoccupation with the maintenance of certain familiar routines (e.g. upset if different route taken to a familiar place; insists on following a complicated bedtime ritual before going to sleep; insists that cutlery, crockery, etc., must be placed on the table in precisely the same order for each meal; eats only a few types of food; always stands up and turns round three times before starting next course at each meal)

- *b Overall pattern of spontaneous activities is limited and repetitive (e.g. plays with same kinds of toys or objects; listens to records repetitively; looks only at the same few books). May appear to move from one activity to another, but the same limited pattern can be detected on careful observation

- +c Is intensely attached to familiar home and dislikes going away e.g. for holidays. The attachment is to the house, not to people living in it.

Item C6. Restricted and repetitive patterns of interests of a verbal or intellectual kind

- *a Asks the same questions or series of questions repeatedly, regardless of the replies received (e.g. How old are you? What colour is your car? Where do you live?) or talks repetitively on one or two themes

- b Acts the role of an object, animal, fictional character or real person in a repetitive, stereotyped way

- *+c Repetitive activities dependent on a good rote memory, ability with numbers, musical ability or visuo-spatial skills (e.g. memorising time tables or routes to places; calendar calculations; arithmetical calculations; games depending on numbers; repetitive playing of one type of music; interests limited to playing a musical instrument; computer games; dismantling and/or assembling models, mechanical objects etc; repetitive drawing of limited types of objects or themes)

- +d Preoccupied with particular subjects; tends to amass facts but usually lacks depth of understanding (e.g. methods of transport; meteorology; genealogy

of royal families the legends of King Arthur, military uniforms; specific imaginary or real people. The subjects may be lurid or frightening, such as details of murders or monsters from outer space).

Item C7. Impairment of spontaneous activities

- a Life style is restricted, empty, routine bound. Has virtually no spontaneous activities apart from those related to the daily routine.

DSM-III-Revised (Draft Criteria) Pervasive Developmental Disorders

299.00 Autistic Disorder

Evidence of abnormality in at least 8 of the following 16 sub-groups of features, with at least two from Group I, one from Group II and one from Group III.

Group I Impairment of social interaction
Sub-groups
A3a-e
A4a-c
A5a-e
A7a-h
A8a-e.

Group II Impairment of communication and imagination
Sub-groups
A1a-f
B1a-b
B3a-c
B3d
B4a
B6a-d

Group III Repetitive activities
Sub-groups
C1a-d
C2d and C3a-c
C4a
C5a-b
C6a-d.

Onset

During infancy or childhood (Specify if onset after 36 months)

DSM-III-R

Group I Impairment of Social Interaction

A3 a - e
(a) Never seeks comfort, Appears to ignore pain, heat, or cold.
(b) Seeks comfort, but only in a mechanical way (e.g., sits on human lap as if person were a chair).

(c) Shows distress if hurt, but does not come for comfort.
(d) Approaches others if hurt, but in a stereotyped way, and does not seek or respond to comforting (e.g., always demands, "put plaster on it" regardless of the cause of pain).
(e) Approaches others, intrudes upon them, may cling tightly to them regardless of the needs and feelings of the person approached. May superficially appear to be seeking comfort or affection, but behaviour has a bizarre, repetitive quality.

A4 a-c
(a) Ignores existence of and walks through and over other people, regardless of their feelings. Is unaware of others 'personal space'.
(b) Indifferent to others' pain or distress or may laugh at others' distress (e.g. if someone falls over or is scolded).
(c) Is distressed by injury or illness in another person, but only because of change of appearance or routine. Does not offer comfort or sympathy.

A5 a-e
(a) No peer friendships despite ample opportunities.
(b) Poor relationships with peers - other children tend to tease and bully.
(c) Wants friends but has poor grasp of the concept of friendship. May refer to all acquaintances, however slight as 'friends'.
(d) Has one 'friend', but has a limited, passive role in the partnership.
(e) Has a friend with the same circumscribed interest - talk 'at' each other mainly concerning this interest.

A7 a-h
(a) Does not reciprocate in lap play (e.g. if mother touches and names child's nose and mouth, the child ignores, or may show some signs of pleasure, but does not reciprocate by touching mother's nose and mouth in his turn).
(b) Does not point things out to others and use eye contact in order to share the pleasure of seeing something interesting (not to be confused with pointing to indicate the desire to obtain an object).
(c) Does not spontaneously bring toys or other possessions to show other people to share pleasure and interest. Does not spontaneously offer others pretend food or drink.
(d) Self chosen play activities are solitary.
(e) Involves other children only as mechanical aids (e.g. to bring objects to add to a construction).
(f) Directs other children as puppets in a repetitive game. No interest in other children's suggestions.
(g) Amiably accepts passive role in other children's play (e.g. as baby in a game of 'mothers and fathers'), but makes little or no contribution.
(h) Engages with one other specific person who has the same circumscribed interest (e.g. train or aeroplane spotting, playing chess). The social interaction is dominated by the one theme.

A8 a-e

(a) No spontaneous imitation of others' actions (though may be taught by having limbs moved for him/her).

(b) Automatic, mechanical imitation of others' actions with real appreciation of the meaning, sometimes amounting to echopraxia equivalent to echolalia in speech).

(c) May imitate simple movements, but fails to engage in imitative make-believe play (e.g. does not pretend to be mother or father, teacher, doctor or nurse).

(d) Does imitate actions of one person, animal or object (e.g. a character seen on television, a horse, a train, a robot), but does this repetitively in a stereotyped fashion and is difficult to divert from this activity).

(e) Does try to imitate other people's actions, and is aware of necessity for correct social behaviour, but gets details wrong in a naive, even bizarre fashion. (May be able to learn a sequence of actions, e.g. for a stage performance but only if taught each step in detail).

Group II Impairment of Communication and Imagination

A1 a-f

(a) Does not anticipate being held (e.g. by lifting arms, changing posture, showing eagerness in facial expression).

(b) Does not adapt posture, cuddle in when held, may stiffen and resist when held.

(c) Does not look or smile when making a social approach.

(d) Does not use eye contact to get someone's attention. May make eye contact in brief glances only, but not for the purpose of gaining another's attention.

(e) Does make eye contact, but does so inappropriately (e.g. stares too long and hard; holds someone's face and looks closely into their eyes when wanting their attention).

(f) Does make social approaches, but does not use variations in eye to eye gaze, etc., or vocalisations such as "um" or "ah" to punctuate conversations and to guide turn taking.

B1 a-b

(a) In the pre-verbal stages of development, no meaningful intoned vocalisations, or communicative babbling, plus failure to compensate by alternative methods of communication such as facial expression and simple gestures.

(b) At a stage when speech should be present, has no spoken language (often with a history as in (a) above), and fails to compensate with gesture and mime, apart from pulling others' hands or arms in a mechanical way, or simple pointing.

B3 a-c

(a) Stereotyped and repetitive use of speech; immediate echolalia and/or repetition of phrases in a mechanical way (The latter can vary from a

vocabulary of a few words only used repetitively without meaning, to television commercials or even whole conversations repeated in the tones and accents of the original speakers). Such stereotyped phrases may also be used to obtain simple needs.

(b) Problems with words that change meaning with the context (pronouns, prepositions, words relating to time etc.). Most obviously shown in the reversal of pronouns (e.g. "you want cookie").

(c) Idiosyncratic use of words or phrases. These may be incorrect, concrete, literal, inverted, or actual neologisms (e.g. "earring plugs" for "ear-phones"; "shake-milk" for "milk-shake"; "go on green ridings" for "go on the swing in the park", "cushion" for apple puree).

B3 d

(d) Grammatical speech and large vocabulary, but use of speech long-winded, pedantic, lacking in colloquialisms, repetitive (e.g. "I wish to thank you for the hospitality you have extended to me this afternoon" instead of "thanks for the cup of tea").

B4 a

(a) Abnormalities in pitch, stress, rate, rhythm, volume or intonation of speech (e.g. speech monotonous, voice inappropriately high or low pitched; statements always have a questioning melody regardless of content).

B6 a-d

(a) No appropriate use of miniature objects, despite language comprehension age of 2 years or above (e.g. handles toys only to obtain simple sensory stimuli, does not lay toy tea table with toy crockery, does not imitate car noises and pretend to drive toy car).

(b) Shows appropriate use of miniature objects when presented in a test situation, but does so in a limited mechanical fashion without elaboration of pretence and does not choose to play with toys spontaneously.

(c) Uses some toys spontaneously in an appropriate way, but play is repetitive and does not include the use of one object to represent another (e.g. a banana to represent a telephone).

(d) Has representational play, which may be elaborate (e.g. using wooden blocks to build a complex network of roads and bridges) but this is limited to the one theme and is markedly repetitive.

Group III Repetitive Activities

C1 a-d

(a) Tends to stay in one position with little or no spontaneous activity (e.g. sits with legs tucked up and head bowed).

(b) Moves around aimlessly (e.g. wanders; runs; makes rapid darting movements; paces to and fro).

(c) Simple repetitive bodily movements (e.g. rocking; teeth grinding; tapping parts of own body).

(d) More complex repetitive movements (e.g. hands and finger twisting or flicking; complex whole body movements).

C2 d and C3 a-c

(d) Preoccupation with visual, auditory, olfactory or tactile sensations (e.g. looks through fingers at lights; fascinated by watching things spin; listens to sounds made by water in radiators; deliberately plays records at the wrong speed; smells objects and/or people; feels, or scratches, or taps on different surfaces).
and

(a) Unusual attachment to objects (e.g. insists on carrying round a particular object such as a belt; a toy car; a stone; and empty detergent packet).

(b) 'Collects' certain kinds of objects for no apparent purpose (e.g. dead holly leaves; wrappers from one brand chocolate; small tea pots; books on a specific subject which may remain unread; toy trains). Tends to notice and react even if one item missing.

(c) Arranges objects in straight lines or patterns - may be upset if arrangements are disturbed.

C4 a

(a) Preoccupied with the maintenance of small, often trivial aspects of the environment (e.g. disproportionately upset if things are broken or blemished; resists changes in arrangements of ornaments; upset if given a different brand of a particular food or drink; refuses to wear new shoes or other new clothes). For some, the maintenance of sameness is shown by stubborn determination not to accept change and ingenious ways of returning to the preferred pattern, but without overt distress or a temper tantrum. The rating should be made on the evidence that the person strongly prefers that sameness be maintained as in the above examples.

C5 a-b *(b is defined here but was not included in the ADDC Wing 1987, See Appendix A)*

(a) Preoccupied with the maintenance of certain familiar routines (e.g. upset if different route taken to a familiar place; insists on following a complicated bedtime ritual before going to sleep; insists that cutlery, crockery, etc., must be placed on the table in precisely the same order for each meal; eats only a few types of food; always stands up and turns round three times before starting next course of each meal).

(b) Overall pattern of spontaneous activities is limited and repetitive (e.g. "plays" with same kinds of toys or objects; listens to records repetitively; looks only at the same few books). May appear to move from one activity to another, but the same limited pattern can be detected on careful observation.

C6 a-d *(c has slightly different wording in ADDC Wing 1987, See Appendix A)*

(a) Asks same questions or series of questions repeatedly, regardless of the replies (e.g. How old are you? What colour is your car? Where do you live?) or talks repetitively on one or two themes.

(b) Acts the role of an object, animal, or fictional character or real person in a repetitive, stereotyped way.

(c) Repetitive activities dependent on a good rote memory ability with number, musical ability or visuo-spatial skills (e.g. memorising time tables or routes to places; calendar calculations; arithmetical calculations; games depending on numbers; repetitive playing of one type of music; interests limited to playing a musical instrument; computer games; dismantling and/or assembling models, mechanical objects etc.; repetitive drawing of limited types of objects or themes).

(d) Preoccupied with particular subjects; tends to amass facts but usually lacks depth of understanding (e.g. methods of transport; meteorology; genealogy of royal families; the legends of King Arthur; military uniforms; specific imaginary or real people. The subjects may be lurid or frightening, such as details of murders or monsters from outer space).

ICD 10 Draft Research Criteria Pervasive Developmental Disorders

F84.0 Childhood Autism

Demonstrable abnormalities in at least three of the sub-groups of features in Group I, two in Group II and two in Group III.

Group I Impairment of social interaction

Sub-groups

A1a-f
A3a-e; A4a-d
A4e
A5a-e
A6a-e

Group II Impairment of communication and imagination

Sub-groups

B1a-b
B1c-d
B3a-c
B4a
B6a-d

Group III Repetitive activities

Sub-groups

C1d
C3a-b
C3c,e, C5a
C3d,f
C4a
C5b

Onset

Presence of abnormal/impaired development from before the age of 36 months, shown in at least one of the following areas:

(1) Receptive and/or expressive language as used in social communication

(2) Development of selective social attachments and/or reciprocal social interaction

(3) Functional and/or symbolic play.

Group I Impairment of Social Interaction

A1 a-f

(a) Does not anticipate being held (e.g. by lifting arms, changing posture, showing eagerness in facial expression).
(b) Does not adapt posture, cuddle in when held, may stiffen and resist when held.
(c) Does not look or smile when making a social approach.
(d) Does not use eye contact to get someone's attention. May make eye contact in brief glances only, but not for the purpose of gaining another's attention.
(e) Does make eye contact, but does so inappropriately (e.g. stares too long and hard; holds someone's face and looks closely into their eyes when wanting their attention).
(f) Does make social approaches, but does not use variations in eye to eye gaze, etc., or vocalisations such as "um" or "ah" to punctuate conversations and to guide turn taking.

A3 a-e and A4 a-d

(a) Never seeks comfort, Appears to ignore pain, heat, or cold.
(b) Seeks comfort, but only in a mechanical way (e.g., sits on human lap as if person were a chair).
(c) Shows distress if hurt, but does not come for comfort.
(d) Approaches others if hurt, but in a stereotyped way, and does not seek or respond to comforting (e.g., always demands, "put plaster on it" regardless of the cause of pain).
(e) Approaches others, intrudes upon them, may cling tightly to them regardless of the needs and feelings of the person approached. May superficially appear to be seeking comfort or affection, but behaviour has a bizarre, repetitive quality.

and

(a) Ignores existence of and walks through and over other people, regardless of their feelings. Is unaware of others 'personal space'.
(b) Indifferent to others' pain or distress or may laugh at others' distress (e.g. if someone falls over or is scolded).
(c) Is distressed by injury or illness in another person, but only because of change of appearance or routine. Does not offer comfort or sympathy.
(d) No intuitive sympathy with others' pain or distress, but has some understanding on an intellectual level if problem is explained. May then try to offer comfort and sympathy, but may do this in a naive and inappropriate manner.

A4 e *Question not in the ADDC Wing (1987 - Personal Communication)*

A5 a-e

(a) No peer friendships despite ample opportunities.

(b) Poor relationships with peers - other children tend to tease and bully.
(c) Wants friends but has poor grasp of the concept of friendship. May refer to all acquaintances, however slight as 'friends'.
(d) Has one 'friend', but has a limited, passive role in the partnership.
(e) Has a friend with the same circumscribed interest - talk 'at' each other mainly concerning this interest.

A6 a-e *(e defined here but was not in the ADDC Wing 1987, See Appendix A)*

(a) Lack of awareness of need for personal modesty (e.g. will remove clothing or appear naked in any company, in complete innocence).
(b) Lack of awareness of psychological barriers (e.g. invades other people's 'personal space'; walks behind counters in shops; enters other people's houses to 'collect' a particular object).
(c) Lack of awareness of correct behaviour in public (e.g. screams in public; removes objects from shelves in shops; sits down in puddles in middle of road).
(d) Lack of awareness of social taboos in conversation (e.g. makes naive, embarrassing personal remarks in public; talks about delicate subjects in a loud voice in company; asks strangers inappropriate, embarrassing questions).
(e) Lack of awareness of and/or inappropriate response to other people's emotions.

Group II Impairment of Communication and Imagination

B1 a-b

(a) In the pre-verbal stages of development, no meaningful intoned vocalisations, or communicative babbling, plus failure to compensate by alternative methods of communication such as facial expression and simple gestures.
(b) At a stage when speech should be present, has no spoken language (often with a history as in (a) above), and fails to compensate with gesture and mime, apart from pulling others' hands or arms in a mechanical way, or simple pointing.

B1 c-d

(c) Has speech, but neither initiates nor sustains a conversation with others
(d) Make approaches to others, but content of speech is one-sided, repetitive, without appropriate conversational turn-taking.

B3 a-c

(a) Stereotyped and repetitive use of speech; immediate echolalia and/or repetition of phrases in a mechanical way (The latter can vary from a vocabulary of a few words only used repetitively without meaning, to television commercials or even whole conversations repeated in the tones

and accents of the original speakers). Such stereotyped phrases may also be used to obtain simple needs.
(b) Problems with words that change meaning with the context (pronouns, prepositions, words relating to time etc.). Most obviously shown in the reversal of pronouns (e.g. "you want cookie").
(c) Idiosyncratic use of words or phrases. These may be incorrect, concrete, literal, inverted, or actual neologisms (e.g. "earring plugs" for "ear-phones"; "shake-milk" for "milk-shake"; "go on green ridings" for "go on the swing in the park", "cushion" for apple puree).

B4 a

(a) Abnormalities in pitch, stress, rate, rhythm, volume or intonation of speech (e.g. speech monotonous, voice inappropriately high or low pitched; statements always have a questioning melody regardless of content).

B6 a-d

(a) No appropriate use of miniature objects, despite language comprehension age of 2 years or above (e.g. handles toys only to obtain simple sensory stimuli, does not lay toy tea table with toy crockery, does not imitate car noises and pretend to drive toy car).
(b) Shows appropriate use of miniature objects when presented in a test situation, but does so in a limited mechanical fashion without elaboration of pretence and does not choose to play with toys spontaneously.
(c) Uses some toys spontaneously in an appropriate way, but play is repetitive and does not include the use of one object to represent another (e.g. a banana to represent a telephone).
(d) Has representational play, which may be elaborate (e.g. using wooden blocks to build a complex network of roads and bridges) but this is limited to the one theme and is markedly repetitive.

Group III Repetitive Activities

C1 d

(d) More complex repetitive movements (e.g. hands and finger twisting or flicking; complex whole body movements).

C3 a-b

(a) Unusual attachment to objects (e.g. insists on carrying round a particular object such as a belt; a toy car; a stone; and empty detergent packet).
(b) 'Collects' certain kinds of objects for no apparent purpose (e.g. dead holly leaves; wrappers from one brand chocolate; small tea pots; books on a specific subject which may remain unread; toy trains). Tends to notice and react even if one item missing.

C3 c, e and C5a

(c) Arranges objects in straight lines or patterns - may be upset if arrangements are disturbed.

(e) Preoccupied with repetitive actions, involving objects (e.g. flicks pieces of string or other materials; turns light switches on and off; spins the wheels of toy cars; pours water from one vessel to another).
and

C5

(a) Preoccupied with the maintenance of certain familiar routines (e.g. upset if different route taken to a familiar place; insists on following a complicated bedtime ritual before going to sleep; insists that cutlery, crockery, etc., must be placed on the table in precisely the same order for each meal; eats only a few types of food; always stands up and turns round three times before starting next course of each meal).

C3 d, f

(d) Preoccupation with parts of objects, animals or people (e.g. fascinated by animal's fur; people's teeth; church steeples; one or two bars of music out of a complete recording; the smell of objects; the feel of the surface; the noise objects make when shaken, tapped, thrown or if wheels are spun etc.).

(f) Preoccupation with specific abstract attributes of objects or people, such as colour, shape, sound, number (e.g. fascinated with anything that is yellow, or round in shape, regardless of its practical function; identifies people by their numerical attributes such as age, house numbers).

C4 a

(a) Preoccupied with the maintenance of small, often trivial aspects of the environment (e.g. disproportionately upset if things are broken or blemished; resists changes in arrangements of ornaments; upset if given a different brand of a particular food or drink; refuses to wear new shoes or other new clothes). For some, the maintenance of sameness is shown by stubborn determination not to accept change and ingenious ways of returning to the preferred pattern, but without overt distress or a temper tantrum. The rating should be made on the evidence that the person strongly prefers that sameness be maintained as in the above examples.

C5 b *(b is defined here but was not included in the ADDC Wing 1987, See Appendix A)*

(b) Overall pattern of spontaneous activities is limited and repetitive (e.g. "plays" with same kinds of toys or objects; listens to records repetitively; looks only at the same few books). May appear to move from one activity to another, but the same limited pattern can be detected on careful observation.

Kanner Early Infantile Autism

The features described by Kanner in his papers are marked (*) in the check list. Kanner did not operationalise his criteria but suggestions are made below for arbitrary cut-off points in order to provide a definition to be tested.

Kanner's 5 criteria

Kanner and Eisenberg (1956) discussed diagnosis. They listed 5 features that Kanner originally considered to be essential, as follows:

I Profound lack of affective contact
(Criteria - 6 or more examples of features marked * in Section A of the checklist)

II Mutism or language not used for social communication
(Criteria - 3 or more examples of features marked * in Section B of the checklist).

III An anxiously obsessive desire for maintenance of sameness resulting in a marked limitation in the variety of spontaneous activity
(Criteria - 1 or more examples of features marked * in Section C of the checklist).

IV Fascination with objects which are handled with skill in fine motor movements
(Criteria - 1 example of features in Item C 3a-e and skill in object manipulation - the latter must be judged by observation or informant's report).

V Good cognitive potential shown by feats of memory or skill with visuo-spatial tasks, such as the Seguin formboard
(Criteria - Presence of Item C 3c and/or relevant skills shown on testing or observation).

Kanner's 5 Criteria (Kanner and Eisenberg, 1956)

I. Profound lack of affective contact
(Criteria - 6 or more examples of features marked * in Section A of the checklist)

A1 a-d

(a) Does not anticipate being held (e.g. by lifting arms, changing posture, showing eagerness in facial expression).

(b) Does not adapt posture, cuddle in when held, may stiffen and resist when held.

(c) Does not look or smile when making a social approach.

(d) Does not use eye contact to get someone's attention. May make eye contact in brief glances only, but not for the purpose of gaining another's attention.

A2 a-c

(a) Does not rush to greet parents after a period of separation.
(b) Does not spontaneously wave to greet or when saying good-bye.
(c) Ignores visitors to the house, classroom etc. (not just because absorbed in some activity).

A3 a - d

(a) Never seeks comfort, Appears to ignore pain, heat, or cold.
(b) Seeks comfort, but only in a mechanical way (e.g., sits on human lap as if person were a chair).
(c) Shows distress if hurt, but does not come for comfort.
(d) Approaches others if hurt, but in a stereotyped way, and does not seek or respond to comforting (e.g., always demands, "put plaster on it" regardless of the cause of pain).

A4 a-b, e *(e defined here but not included in ADDC Wing 1987, See Appendix A)*

(a) Ignores existence of and walks through and over other people, regardless of their feelings. Is unaware of others 'personal space'.
(b) Indifferent to others' pain or distress or may laugh at others' distress (e.g. if someone falls over or is scolded).
(e) Lack of vicarious pleasure on other people's happiness and/or lack of seeking to share happiness or pleasure with others.

A5 a

(a) No peer friendships despite ample opportunities.

A6 a-b, e *(e defined here but not included in ADDC Wing 1987, See Appendix A)*

(a) Lack of awareness of need for personal modesty (e.g. will remove clothing or appear naked in any company, in complete innocence).
(b) Lack of awareness of psychological barriers (e.g. invades other people's 'personal space'; walks behind counters in shops; enters other people's houses to 'collect' a particular object).
(e) Lack of awareness of and/or inappropriate response to other people's emotions.

A7 a-f

(a) Does not reciprocate in lap play (e.g. if mother touches and names child's nose and mouth, the child ignores, or may show some signs of pleasure, but does not reciprocate by touching mother's nose and mouth in his turn).

(b) Does not point things out to others and use eye contact in order to share the pleasure of seeing something interesting (not to be confused with pointing to indicate the desire to obtain an object).
(c) Does not spontaneously bring toys or other possessions to show other people to share pleasure and interest. Does not spontaneously offer others pretend food or drink.
(d) Self chosen play activities are solitary.
(e) Involves other children only as mechanical aids (e.g. to bring objects to add to a construction).
(f) Directs other children as puppets in a repetitive game. No interest in other children's suggestions.

A8 a-c

(a) No spontaneous imitation of others' actions (though may be taught by having limbs moved for him/her).
(b) Automatic, mechanical imitation of others' actions with real appreciation of the meaning, sometimes amounting to echopraxia equivalent to echolalia in speech).
(c) May imitate simple movements, but fails to engage in imitative make-believe play (e.g. does not pretend to be mother or father, teacher, doctor or nurse).

A9 a

(a) Fails to 'animate' toy animals and dolls or objects (e.g. does not show tender care of and feed toy animals or dolls, or walk them along, make noises or talk in the animal's or doll's voices).

II. Mutism or language not used for social communication

(Criteria - 3 or more examples of features marked * in Section B of the checklist)

B1 a-c

(a) In the pre-verbal stages of development, no meaningful intoned vocalisations, or communicative babbling, plus failure to compensate by alternative methods of communication such as facial expression and simple gestures.
(b) At a stage when speech should be present, has no spoken language (often with a history as in (a) above), and fails to compensate with gesture and mime, apart from pulling others' hands or arms in a mechanical way, or simple pointing.
(c) Has speech, but neither initiates nor sustains a conversation with others.

B2 a-c

(a) No response to communication from others, (e.g. does not respond to own name).
(b) Responds to communication of simple instructions, but only in familiar context; actions due to learned habits rather than to understanding of words.
(c) Response to single words or phrases out of context, rather than the meaning of a whole statement (e.g. mother, while doing the dishes, says "I've torn

my glove, would you get me another pair please". Child goes out of kitchen and returns with a pair of woollen gloves).

B3 a-c

(a) Stereotyped and repetitive use of speech; immediate echolalia and/or repetition of phrases in a mechanical way (The latter can vary from a vocabulary of a few words only used repetitively without meaning, to television commercials or even whole conversations repeated in the tones and accents of the original speakers). Such stereotyped phrases may also be used to obtain simple needs.

(b) Problems with words that change meaning with the context (pronouns, prepositions, words relating to time etc.). Most obviously shown in the reversal of pronouns (e.g. "you want cookie").

(c) Idiosyncratic use of words or phrases. These may be incorrect, concrete, literal, inverted, or actual neologisms (e.g. "earring plugs" for "ear-phones"; "shake-milk" for "milk-shake"; "go on green ridings" for "go on the swing in the park", "cushion" for apple puree).

B4 a

(a) Abnormalities in pitch, stress, rate, rhythm, volume or intonation of speech (e.g. speech monotonous, voice inappropriately high or low pitched; statements always have a questioning melody regardless of content).

B6 a-c

(a) No appropriate use of miniature objects, despite language comprehension age of 2 years or above (e.g. handles toys only to obtain simple sensory stimuli, does not lay toy tea table with toy crockery, does not imitate car noises and pretend to drive toy car).

(b) Shows appropriate use of miniature objects when presented in a test situation, but does so in a limited mechanical fashion without elaboration of pretence and does not choose to play with toys spontaneously.

(c) Uses some toys spontaneously in an appropriate way, but play is repetitive and does not include the use of one object to represent another (e.g. a banana to represent a telephone).

III. An anxiously obsessive desire for maintenance of sameness resulting in a marked limitation in the variety of spontaneous activity.
(Criteria - 1 or more examples of features marked * in Section C of the checklist).

C1 d

(d) More complex repetitive movements (e.g. hands and finger twisting or flicking; complex whole body movements).

C2 d

(d) Preoccupation with visual, auditory, olfactory or tactile sensations (e.g. looks through fingers at lights; fascinated by watching things spin; listens to

sounds made by water in radiators; deliberately plays records at the wrong speed; smells objects and/or people; feels, or scratches, or taps on different surfaces).

C3 a-f

(a) Unusual attachment to objects (e.g. insists on carrying round a particular object such as a belt; a toy car; a stone; and empty detergent packet).

(b) 'Collects' certain kinds of objects for no apparent purpose (e.g. dead holly leaves; wrappers from one brand chocolate; small tea pots; books on a specific subject which may remain unread; toy trains). Tends to notice and react even if one item missing.

(c) Arranges objects in straight lines or patterns - may be upset if arrangements are disturbed.

(d) Preoccupation with parts of objects, animals or people (e.g. fascinated by animal's fur; people's teeth; church steeples; one or two bars of music out of a complete recording; the smell of objects; the feel of the surface; the noise objects make when shaken, tapped, thrown or if wheels are spun etc.).

(e) Preoccupied with repetitive actions, involving objects (e.g. flicks pieces of string or other materials; turns light switches on and off; spins the wheels of toy cars; pours water from one vessel to another).

(f) Preoccupation with specific abstract attributes of objects or people, such as colour, shape, sound, number (e.g. fascinated with anything that is yellow, or round in shape, regardless of its practical function; identifies people by their numerical attributes such as age, house numbers).

C4 a

(a) Preoccupied with the maintenance of small, often trivial aspects of the environment (e.g. disproportionately upset if things are broken or blemished; resists changes in arrangements of ornaments; upset if given a different brand of a particular food or drink; refuses to wear new shoes or other new clothes). For some, the maintenance of sameness is shown by stubborn determination not to accept change and ingenious ways of returning to the preferred pattern, but without overt distress or a temper tantrum. The rating should be made on the evidence that the person strongly prefers that sameness be maintained as in the above examples.

C5 a-b *(b is defined here but was not included in the ADDC Wing 1987, See Appendix A)*

(a) Preoccupied with the maintenance of certain familiar routines (e.g. upset if different route taken to a familiar place; insists on following a complicated bedtime ritual before going to sleep; insists that cutlery, crockery, etc., must be placed on the table in precisely the same order for each meal; eats only a few types of food; always stands up and turns round three times before starting next course of each meal).

(b) Overall pattern of spontaneous activities is limited and repetitive (e.g. "plays" with same kinds of toys or objects; listens to records repetitively; looks only at the same few books). May appear to move from one activity to another, but the same limited pattern can be detected on careful observation.

C6 a, c *(c has slightly different wording in ADDC Wing 1987, See Appendix A)*

(a) Asks same questions or series of questions repeatedly, regardless of the replies (e.g. How old are you? What colour is your car? Where do you live?) or talks repetitively on one or two themes.

(c) Repetitive activities dependent on a good rote memory ability with number, musical ability or visuo-spatial skills (e.g. memorising time tables or routes to places; calendar calculations; arithmetical calculations; games depending on numbers; repetitive playing of one type of music; interests limited to playing a musical instrument; computer games; dismantling and/or assembling models, mechanical objects etc.; repetitive drawing of limited types of objects or themes).

IV. Fascination with objects which are handled with skill in fine motor movements.

(Criteria - 1 example of features in Item C 3a-e and skill in objects manipulation (the latter must be judged by observation or informant's report)

C3 a-e

(a) Unusual attachment to objects (e.g. insists on carrying round a particular object such as a belt; a toy car; a stone; and empty detergent packet).

(b) 'Collects' certain kinds of objects for no apparent purpose (e.g. dead holly leaves; wrappers from one brand chocolate; small tea pots; books on a specific subject which may remain unread; toy trains). Tends to notice and react even if one item missing.

(c) Arranges objects in straight lines or patterns - may be upset if arrangements are disturbed.

(d) Preoccupation with parts of objects, animals or people (e.g. fascinated by animal's fur; people's teeth; church steeples; one or two bars of music out of a complete recording; the smell of objects; the feel of the surface; the noise objects make when shaken, tapped, thrown or if wheels are spun etc.).

(e) Preoccupied with repetitive actions, involving objects (e.g. flicks pieces of string or other materials; turns light switches on and off; spins the wheels of toy cars; pours water from one vessel to another).

V. Good cognitive potential shown by feats of memory or skill with visuo-spatial tasks, such as the Sequin formboard.

(Criteria - Presence of Item C3c and/or relevant skills shown on testing or observation)

C3c

(c) Arranges objects in straight lines or patterns - may be upset if arrangements are disturbed.

Kanner and Eisenberg's 2 criteria

Kanner & Eisenberg (1956) went on to suggest that only 2 criteria were in fact essential, because their presence implied that the rest would be found. The 2 were:

I Profound lack of affective contact
(Criteria as for 1. above).

II Preservation of sameness shown in 'elaborately conceived rituals'
(Criteria - 1 or more examples from Items c 1d; C 3b; c; e; f; C 4a; C 5a; C 6a-c).

Onset

Present in typical form before 30 months and up to at least 6 or 7 years of age; the features tend to change in their manifestations with increasing age.

Asperger's Syndrome

The features described by Asperger are marked (+) in the text (see pages 350 - 358). He gave no list of criteria but the following are the major features he described, with suggestions for arbitrary diagnostic criteria from the checklist.

I Impairment of reciprocal social interaction shown by inappropriate, one sided, odd approaches to others or a cold, stiff, distant manner
(Criteria - 4 or more examples of the features marked + in Section A Items 2-9 the checklist).

II Speech which is formal, pedantic, long winded and repetitive.
Understanding of speech tends to be literal
(Criteria - 1 or more examples from Items B 1d; B 2d; B 3d).

III Intonation is monotonous, odd or inappropriate in relation to the meaning
(Criterion - Items B 4a).

IV Impairment of non-verbal communication
(Criteria - 2 or more examples from Item A 1e; f; Item B 5a; b).

V Circumscribed interests followed to the exclusion of other activities
(Criterion - Item C 6c and/or C 6d).

(VI Poor motor co-ordination is an additional feature described by Asperger but not included in the checklist).

Onset

In typical cases, the child starts to talk before walking; abnormalities are not noticed by parents before 36 months and sometimes not until the child starts school. However, Asperger did not give details of the types of questions asked to elicit the early developmental history.

Asperger's Syndrome

I. Impairment in reciprocal social interaction shown by inappropriate, one sided, odd approaches to others or a cold, stiff, distant manner.
(Criteria - 4 or more examples of the features marked + in Section A Items 2-9 of the checklist - see pages 350 - 358).

A2 e

(e) Makes approaches indiscriminately and inappropriately to familiar people and strangers alike.

A4 c-e *(e is defined here but was not included in the ADDC Wing 1987, See Appendix A)*

(c) Is distressed by injury or illness in another person, but only because of change of appearance or routine. Does not offer comfort or sympathy.

(d) No intuitive sympathy with others' pain or distress, but has some understanding on an intellectual level if problem is explained. May then try to offer comfort and sympathy, but may do this in a naive and inappropriate manner.

(e) Lack of vicarious pleasure on other people's happiness and/or lack of seeking to share happiness or pleasure with others.

A5 a-e

(a) No peer friendships despite ample opportunities.

(b) Poor relationships with peers - other children tend to tease and bully.

(c) Wants friends but has poor grasp of the concept of friendship. May refer to all acquaintances, however slight as 'friends'.

(d) Has one 'friend', but has a limited, passive role in the partnership.

(e) Has a friend with the same circumscribed interest - talk 'at' each other mainly concerning this interest.

A6 d-e

(d) Lack of awareness of social taboos in conversation (e.g. makes naive, embarrassing personal remarks in public; talks about delicate subjects in a loud voice in company; asks strangers inappropriate, embarrassing questions).

(e) Lack of awareness of and/or inappropriate response to other people's emotions.

A7 g-h

(g) Amiably accepts passive role in other children's play (e.g. as baby in a game of 'mothers and fathers'), but makes little or no contribution.

(h) Engages with one other specific person who has the same circumscribed interest (e.g. train or aeroplane spotting, playing chess). The social interaction is dominated by the one theme.

A9 b-c

(b) Does appear to 'animate' one or a few toys or other objects, but does so in a limited repetitive way and continues with the same activity for long periods. 'Play' does not become more elaborate with time.

(c) Invents a fantasy person or people, even an entire imaginary world, but the fantasy activities are concentrated on one or a few limited themes and are repetitive in quality (e.g. invents a fantasy family of people, but is concerned solely with talking about the details of the family tree - who is related to whom, and how - all of which are remembered with complete precision).

II. Speech which is formal, pedantic, long winded and repetitive. Understanding of speech tends to be literal.
(Criteria - 1 or more examples from Item B1d; B2d; B3d).

B1 d

(d) Make approaches to others, but content of speech is one-sided, repetitive, without appropriate conversational turn-taking.

B2 d

(d) Understand a wide range of words and grammatical constructions, but has marked tendency to interpret information in a literal way, failing to take the context in to account. Leading to naive mistakes (e.g. mother making a cake, says to 15 year old autistic son "I need some cloves. Take some money from my purse and buy me some". Boy mishears, but asks no questions and returns some hours later with bag full of teen-age girl's clothes).

B3 d

(d) Grammatical speech and large vocabulary, but use of speech long-winded, pedantic, lacking in colloquialisms, repetitive (e.g. "I wish to thank you for the hospitality you have extended to me this afternoon" instead of "thanks for the cup of tea").

III. Intonation is monotonous, odd or inappropriate in relation to the meaning.
(Criterion B4a)

B4 a

(a) Abnormalities in pitch, stress, rate, rhythm, volume or intonation of speech (e.g. speech monotonous, voice inappropriately high or low pitched; statements always have a questioning melody regardless of content).

IV. Impairment of non-verbal communication.
(Criteria - 2 or more examples from Item A1e, f; Item B5a, b)

A1 e-f

(e) Does make eye contact, but does so inappropriately (e.g. stares too long and hard; holds someone's face and looks closely into their eyes when wanting their attention).

(f) Does make social approaches, but does not use variations in eye to eye gaze, etc., or vocalisations such as "um" or "ah" to punctuate conversations and to guide turn taking.

B5 a-b *(a,b defined here but were not included in the ADDC Wing 1987. See Appendix A)*

(a) Little or no use of non-verbal communication (body language) (e.g. gesture; facial expression; body posture and movement; degree of nearness to others

etc.) to accompany speech, to substitute for speech or to express feeling towards others.

(b) Does use non-verbal communication but in an exaggerated, inappropriate way that looks odd.

V. Circumscribed interests followed to the exclusion of other activities.
(Criterion - Item C6c or C6 d)

C6 c-d

(c) Repetitive activities dependent on a good rote memory ability with number, musical ability or visuo-spatial skills (e.g. memorising time tables or routes to places; calendar calculations; arithmetical calculations; games depending on numbers; repetitive playing of one type of music; interests limited to playing a musical instrument; computer games; dismantling and/or assembling models, mechanical objects etc.; repetitive drawing of limited types of objects or themes).

(d) Preoccupied with particular subjects; tends to amass facts but usually lacks depth of understanding (e.g. methods of transport; meteorology; genealogy of royal families; the legends of King Arthur; military uniforms; specific imaginary or real people. The subjects may be lurid or frightening, such as details of murders or monsters from outer space).

(VI. Poor motor coordination is an additional feature described by Asperger but not included in the checklist).

Wing and Gould Continuum of Autistic Disorders

In an epidemiological study in the Camberwell area of London (Wing and Gould, 1979), the presence of autistic continuum disorders was diagnosed from the developmental history and the systematic recording of present behaviour using the Handicaps Behaviour and Skills (HBS) schedule (Wing & Gould, 1978). A disorder of this kind was considered to be present if the behaviour pattern was dominated by impairment of social interaction, communication and imagination and repetitive, stereotyped behaviour. No precise rules and cut-off points were defined.

For the purpose of this checklist, arbitrary rules are suggested as below.

Triad of Impairments of Social Interaction, Communication and Imagination

I Impairments of reciprocal social interaction
(Criteria - 3 or more examples of features from Section A Items 1- 6).

II Impairment of social communication
(Criteria - 2 or more examples of features from Section B Items 1 - 5).

III Impairments of symbolic development and/or social imagination
(Criteria - 2 or more examples of features from Section A Items 7 - 9; Section B Item 6).

IV Rigid, repetitive, stereotyped pattern of activities
(Criteria - 1 or more examples of features from Section C any Items).

Impairment of Social Interaction

The presence of impairment of social interaction on its own is associated with a range of problems in childhood and adult life
(Criteria - as for I above).

Triad of impairment of Social Interaction, Communication and Imagination.

I. Impairment of reciprocal social interaction.
(Criteria - 3 or more examples of features from Section A Items 1-6).

A1 a-f

(a) Does not anticipate being held (e.g. by lifting arms, changing posture, showing eagerness in facial expression).
(b) Does not adapt posture, cuddle in when held, may stiffen and resist when held.
(c) Does not look or smile when making a social approach.

(d) Does not use eye contact to get someone's attention. May make eye contact in brief glances only, but not for the purpose of gaining another's attention.
(e) Does make eye contact, but does so inappropriately (e.g. stares too long and hard; holds someone's face and looks closely into their eyes when wanting their attention).
(f) Does make social approaches, but does not use variations in eye to eye gaze, etc., or vocalisations such as "um" or "ah" to punctuate conversations and to guide turn taking.

A2 a-e

(a) Does not rush to greet parents after a period of separation.
(b) Does not spontaneously wave to greet or when saying good-bye.
(c) Ignores visitors to the house, classroom etc. (not just because absorbed in some activity).
(d) Says 'hello' or some stereotyped phrase but only when prompted, or because of previous training.
(e) Makes approaches indiscriminately and inappropriately to familiar people and strangers alike.

A3 a-e

(a) Never seeks comfort, Appears to ignore pain, heat, or cold.
(b) Seeks comfort, but only in a mechanical way (e.g., sits on human lap as if person were a chair).
(c) Shows distress if hurt, but does not come for comfort.
(d) Approaches others if hurt, but in a stereotyped way, and does not seek or respond to comforting (e.g., always demands, "put plaster on it" regardless of the cause of pain).
(e) Approaches others, intrudes upon them, may cling tightly to them regardless of the needs and feelings of the person approached. May superficially appear to be seeking comfort or affection, but behaviour has a bizarre, repetitive quality.

A4 a-e *(e defined here but not included in ADDC Wing 1987, See Appendix A)*

(a) Ignores existence of and walks through and over other people, regardless of their feelings. Is unaware of others 'personal space'.
(b) Indifferent to others' pain or distress or may laugh at others' distress (e.g. if someone falls over or is scolded).
(c) Is distressed by injury or illness in another person, but only because of change of appearance or routine. Does not offer comfort or sympathy.
(d) No intuitive sympathy with others' pain or distress, but has some understanding on an intellectual level if problem is explained. May then try to offer comfort and sympathy, but may do this in a naive and inappropriate manner.
(e) Lack of vicarious pleasure on other people's happiness and/or lack of seeking to share happiness or pleasure with others.

A5 a-e

(a) No peer friendships despite ample opportunities.
(b) Poor relationships with peers - other children tend to tease and bully.
(c) Wants friends but has poor grasp of the concept of friendship. May refer to all acquaintances, however slight as 'friends'.
(d) Has one 'friend', but has a limited, passive role in the partnership.
(e) Has a friend with the same circumscribed interest - talk 'at' each other mainly concerning this interest.

A6 a-e *(e defined here but was not included in ADDC Wing 1987, See Appendix A)*

(a) Lack of awareness of need for personal modesty (e.g. will remove clothing or appear naked in any company, in complete innocence).
(b) Lack of awareness of psychological barriers (e.g. invades other people's 'personal space'; walks behind counters in shops; enters other people's houses to 'collect' a particular object).
(c) Lack of awareness of correct behaviour in public (e.g. screams in public; removes objects from shelves in shops; sits down in puddles in middle of road).
(d) Lack of awareness of social taboos in conversation (e.g. makes naive, embarrassing personal remarks in public; talks about delicate subjects in a loud voice in company; asks strangers inappropriate, embarrassing questions).
(e) Lack of awareness of and/or inappropriate response to other people's emotions.

II Impairment of social communication.
(Criteria - 2 or more examples of features from Section B Items 1-5).

B1 a-d

(a) In the pre-verbal stages of development, no meaningful intoned vocalisations, or communicative babbling, plus failure to compensate by alternative methods of communication such as facial expression and simple gestures.
(b) At a stage when speech should be present, has no spoken language (often with a history as in (a) above), and fails to compensate with gesture and mime, apart from pulling others' hands or arms in a mechanical way, or simple pointing.
(c) Has speech, but neither initiates nor sustains a conversation with others
(d) Make approaches to others, but content of speech is one-sided, repetitive, without appropriate conversational turn-taking.

B2 a-d

(a) No response to communication from others, (e.g. does not respond to own name).
(b) Responds to communication of simple instructions, but only in familiar context; actions due to learned habits rather than to understanding of words.

(c) Response to single words or phrases out of context, rather than the meaning of a whole statement (e.g. mother, while doing the dishes, says "I've torn my glove, would you get me another pair please". Child goes out of kitchen and returns with a pair of woollen gloves).
(d) Understand a wide range of words and grammatical constructions, but has marked tendency to interpret information in a literal way, failing to take the context into account. Leading to naive mistakes (e.g. mother making a cake, says to 15 year old autistic son "I need some cloves. Take some money from my purse and buy me some". Boy mishears, but asks no questions and returns some hours later with bag full of teen-age girl's clothes).

B3 a-d

(a) Stereotyped and repetitive use of speech; immediate echolalia and/or repetition of phrases in a mechanical way (The latter can vary from a vocabulary of a few words only used repetitively without meaning, to television commercials or even whole conversations repeated in the tones and accents of the original speakers). Such stereotyped phrases may also be used to obtain simple needs.
(b) Problems with words that change meaning with the context (pronouns, prepositions, words relating to time etc.). Most obviously shown in the reversal of pronouns (e.g. "you want cookie").
(c) Idiosyncratic use of words or phrases. These may be incorrect, concrete, literal, inverted, or actual neologisms (e.g. "earring plugs" for "ear-phones"; "shake-milk" for "milk-shake"; "go on green ridings" for "go on the swing in the park", "cushion" for apple puree).
(d) Grammatical speech and large vocabulary, but use of speech long-winded, pedantic, lacking in colloquialisms, repetitive (e.g. "I wish to thank you for the hospitality you have extended to me this afternoon" instead of "thanks for the cup of tea").

B4 a

(a) Abnormalities in pitch, stress, rate, rhythm, volume or intonation of speech (e.g. speech monotonous, voice inappropriately high or low pitched; statements always have a questioning melody regardless of content).

B5 a-b *(a,b defined here but were not included in the ADDC Wing 1987, See Appendix A)*

(a) Little or no use of non-verbal communication (body language) (e.g. gesture; facial expression; body posture and movement; degree of nearness to others etc.) to accompany speech, to substitute for speech or to express feeling towards others.
(b) Does use non-verbal communication but in an exaggerated, inappropriate way that looks odd.

III. Impairment of symbolic development and/or social imagination.
(Criteria - 2 or more examples of features from Section A Items 7-9; Section B Item 6)

Section A

A7 a-h

(a) Does not reciprocate in lap play (e.g. if mother touches and names child's nose and mouth, the child ignores, or may show some signs of pleasure, but does not reciprocate by touching mother's nose and mouth in his turn).
(b) Does not point things out to others and use eye contact in order to share the pleasure of seeing something interesting (not to be confused with pointing to indicate the desire to obtain an object).
(c) Does not spontaneously bring toys or other possessions to show other people to share pleasure and interest. Does not spontaneously offer others pretend food or drink.
(d) Self chosen play activities are solitary.
(e) Involves other children only as mechanical aids (e.g. to bring objects to add to a construction).
(f) Directs other children as puppets in a repetitive game. No interest in other children's suggestions.
(g) Amiably accepts passive role in other children's play (e.g. as baby in a game of 'mothers and fathers'), but makes little or no contribution.
(h) Engages with one other specific person who has the same circumscribed interest (e.g. train or aeroplane spotting, playing chess). The social interaction is dominated by the one theme.

A8 a-e

(a) No spontaneous imitation of others' actions (though may be taught by having limbs moved for him/her).
(b) Automatic, mechanical imitation of others' actions with real appreciation of the meaning, sometimes amounting to echopraxia equivalent to echolalia in speech).
(c) May imitate simple movements, but fails to engage in imitative make-believe play (e.g. does not pretend to be mother or father, teacher, doctor or nurse).
(d) Does imitate actions of one person, animal or object (e.g. a character seen on television, a horse, a train, a robot), but does this repetitively in a stereotyped fashion and is difficult to divert from this activity).
(e) Does try to imitate other people's actions, and is aware of necessity for correct social behaviour, but gets details wrong in a naive, even bizarre fashion. (May be able to learn a sequence of actions, e.g. for a stage performance but only if taught each step in detail).

A9 a-c

(a) Fails to 'animate' toy animals and dolls or objects (e.g. does not show tender care of and feed toy animals or dolls, or walk them along, make noises or talk in the animal's or doll's voices).
(b) Does appear to 'animate' one or a few toys or other objects, but does so in a limited repetitive way and continues with the same activity for long periods. 'Play' does not become more elaborate with time.

(c) Invents a fantasy person or people, even an entire imaginary world, but the fantasy activities are concentrated on one or a few limited themes and are repetitive in quality (e.g. invents a fantasy family of people, but is concerned solely with talking about the details of the family tree - who is related to whom, and how - all of which are remembered with complete precision).

Section B

B6 a-d

(a) No appropriate use of miniature objects, despite language comprehension age of 2 years or above (e.g. handles toys only to obtain simple sensory stimuli, does not lay toy tea table with toy crockery, does not imitate car noises and pretend to drive toy car).
(b) Shows appropriate use of miniature objects when presented in a test situation, but does so in a limited mechanical fashion without elaboration of pretence and does not choose to play with toys spontaneously.
(c) Uses some toys spontaneously in an appropriate way, but play is repetitive and does not include the use of one object to represent another (e.g. a banana to represent a telephone).
(d) Has representational play, which may be elaborate (e.g. using wooden blocks to build a complex network of roads and bridges) but this is limited to the one theme and is markedly repetitive.

IV. Rigid, repetitive, stereotyped pattern of activities.
(Criteria - 1 or more examples of features from Section C any items)

C1 a-d

(a) Tends to stay in one position with little or no spontaneous activity (e.g. sits with legs tucked up and head bowed).
(b) Moves around aimlessly (e.g. wanders; runs; makes rapid darting movements; paces to and fro).
(c) Simple repetitive bodily movements (e.g. rocking; teeth grinding; tapping parts of own body).
(d) More complex repetitive movements (e.g. hands and finger twisting or flicking; complex whole body movements).

C2 a-d

(a) Smearing or other manipulation of saliva or excreta.
(b) Searches for and swallows inedible objects (e.g. cigarette ends; small pieces of metal; paper).
(c) Repetitive self injury (e.g. head banging; eye poking; hand biting; self induced vomiting).
(d) Preoccupation with visual, auditory, olfactory or tactile sensations (e.g. looks through fingers at lights; fascinated by watching things spin; listens to sounds made by water in radiators; deliberately plays records at the wrong speed; smells objects and/or people; feels, or scratches, or taps on different surfaces).

C3 a-f

(a) Unusual attachment to objects (e.g. insists on carrying round a particular object such as a belt; a toy car; a stone; and empty detergent packet).

(b) 'Collects' certain kinds of objects for no apparent purpose (e.g. dead holly leaves; wrappers from one brand chocolate; small tea pots; books on a specific subject which may remain unread; toy trains). Tends to notice and react even if one item missing.

(c) Arranges objects in straight lines or patterns - may be upset if arrangements are disturbed.

(d) Preoccupation with parts of objects, animals or people (e.g. fascinated by animal's fur; people's teeth; church steeples; one or two bars of music out of a complete recording; the smell of objects; the feel of the surface; the noise objects make when shaken, tapped, thrown or if wheels are spun etc.).

(e) Preoccupied with repetitive actions, involving objects (e.g. flicks pieces of string or other materials; turns light switches on and off; spins the wheels of toy cars; pours water from one vessel to another).

(f) Preoccupation with specific abstract attributes of objects or people, such as colour, shape, sound, number (e.g. fascinated with anything that is yellow, or round in shape, regardless of its practical function; identifies people by their numerical attributes such as age, house numbers).

C4 a

(a) Preoccupied with the maintenance of small, often trivial aspects of the environment (e.g. disproportionately upset if things are broken or blemished; resists changes in arrangements of ornaments; upset if given a different brand of a particular food or drink; refuses to wear new shoes or other new clothes). For some, the maintenance of sameness is shown by stubborn determination not to accept change and ingenious ways of returning to the preferred pattern, but without overt distress or a temper tantrum. The rating should be made on the evidence that the person strongly prefers that sameness be maintained as in the above examples.

C5 a-c *(b - c are defined here but were not included in the ADDC Wing 1987, See Appendix A)*

(a) Preoccupied with the maintenance of certain familiar routines (e.g. upset if different route taken to a familiar place; insists on following a complicated bedtime ritual before going to sleep; insists that cutlery, crockery, etc., must be placed on the table in precisely the same order for each meal; eats only a few types of food; always stands up and turns round three times before starting next course of each meal).

(b) Overall pattern of spontaneous activities is limited and repetitive (e.g. "plays" with same kinds of toys or objects; listens to records repetitively; looks only at the same few books). May appear to move from one activity to another, but the same limited pattern can be detected on careful observation.

(c) Is intensely attached to familiar home and dislikes going away e.g. for holidays. The attachment is to the house, not to people living in it.

C6 a-d *(c has slightly different wording in ADDC Wing 1987, See Appendix A)*

(a) Asks same questions or series of questions repeatedly, regardless of the replies (e.g. How old are you? What colour is your car? Where do you live?) or talks repetitively on one or two themes.

(b) Acts the role of an object, animal, or fictional character or real person in a repetitive, stereotyped way.

(c) Repetitive activities dependent on a good rote memory ability with number, musical ability or visuo-spatial skills (e.g. memorising time tables or routes to places; calendar calculations; arithmetical calculations; games depending on numbers; repetitive playing of one type of music; interests limited to playing a musical instrument, computer games; dismantling and/or assembling models, mechanical objects etc.; repetitive drawing of limited types of objects or themes).

(d) Preoccupied with particular subjects; tends to amass facts but usually lacks depth of understanding (e.g. methods of transport; meteorology; genealogy of royal families; the legends of King Arthur; military uniforms; specific imaginary or real people. The subjects may be lurid or frightening, such as details of murders or monsters from outer space).

C7 a

(a) Life style is restricted, empty, routine bound. Has virtually no spontaneous activities apart from those related to the daily routine.

Irish Families Under Stress (Summary).

Michael Fitzgerald.

Studies to determine the percentage of children in the community who have psychiatric disorders are critical in a country like Ireland[1] with a high proportion of children in the population.

Ireland has a developing child psychiatric service and therefore epidemiological information is important in assessing the need for services as are the study of psychosocial and individual associations to behaviour and formal child psychiatric disorder. In the future psychotherapy is likely to play a much greater role in psychiatry in Ireland.

ADOLESCENTS

Psychological Stress in Female Adolescents:

In a study of 132 female adolescents attending inner city schools. 15% showed evidence of psychological stress, and attained a total problem score in the clinical range with 11% often crying; 11% often having stomach aches; 6% often using drugs or alcohol; 6% often wishing they were the opposite sex and 7% often having suicidal thoughts[2]. A study of 300 adolescents using the General Health Questionnaire found that 30% had six or more symptoms[3]. In a study of adolescents with spina bifida 38% showed evidence of formal psychiatric disorders on detailed interviewing[4].

Ten year olds:

A study of 2029 fourth class pupils in an Irish urban area found that 20% of the boys and 11% of the girls were behaviourally deviant. 8% of the children were reading 36 months behind chronological age and 1% were found to be intellectually impaired[5].

Social Support and Behaviour Problems in Children:

The levels of social support of Irish children were similar to levels of social support of American children of the same age. Social support from teachers and class males was associated with higher self esteem and developmental appropriateness[6].

Mothers and Children: Ireland versus Malaysia:

Mothers in Malaysia had significantly lower rates of depressive and anxiety symptoms when compared to Irish mothers. This may have been due to the greater cohesion of Malaysian society. There were no differences in the rate of childhood behaviour problems[7].

The Health Status of Mothers and the Hospitalization of Children:

The mothers of hospitalized children with gastroenteritis had significantly higher levels of psychological distress than the home care mothers. There was no difference in the levels of severity of the childrens illness[8]. There was a significant relationship between poor social resources and psychological distress of mothers[9].

Depressed Children:

In a child psychiatric outpatient sample 14% of attenders were depressed[10]. A five year follow up of depressed children found that 50% were still depressed. At the five year follow up point 12% of these not originally depressed were depressed[11]. There was a relationship between personality and depression[12].

Medical Doctors: Management of Ill Children:

Doctors who had special experience with gastroenteritis during training were more likely to hospitalize patients with gastroenteritis[13].

A Study of Group versus Individual Therapy:

Group and individual psychotherapy showed statistically significant improvements. Those in individual therapy had interpersonal goals while those in group therapy had interpersonal goals at the beginning of treatment[14].

Schizophrenia:

The diagnosis schizophrenia can be used too liberally and an example is Wittgenstein where this diagnosis was applied when in actual fact he suffered from depression[15].

Paediatric Outpatients:

Considerable psychopathology was found in children, parents attending paediatric outpatients[16].

Psychotherapy and the Health Service:

Psychotherapy reduces the utilization of medical services by 20%[17].

Problem Solving Skills in children:

The lack of development of planning skills and negative attunement by parents was considered to be of importance in child rearing[18,19].

A Follow Up Study of Boys with Delinquency:

When a group of 50 boys with delinquent behaviour were followed up it was found that 20% had drug problems with a 92% recidivist rate[20].

Disadvantage and Psychiatric Problems:

Disadvantage and social disconnection were major factors associated with child and maternal psychiatric problems[21].

Maternal Depression and Childhood Behaviour Problems:

There was no statistical association between maternal antenatal depression and child behaviour problems but there was a six times increased risk of behaviour problems in the child if mother was currently depressed. A screening study of mothers postnatally showed that 38% (19) showed evidence of depression. Twenty two per cent had financial difficulties; 10% were on antidepressants and 30% became pregnant sooner than they wanted to[22,62].

Psychosocial Problems Antenatally in a Disadvantaged Area:

Fifty per cent of the women reported symptoms of unhappiness and depression with 11% feeling that life was not worth living. There was considerable evidence of financial and relationship problems[23].

Psychological factors affecting the management of childhood illness:

An anxious mother was a factor in a doctors decision to hospitalise a child[24]. Other factors influencing the doctor were:

(a) Having had a bad experience of gastroenteritis.

(b) Being a male doctor.

(c) Being in single practice.

(d) Making a higher estimate of the severity of the gastroenteritis.

PRIMARY SCHOOL CHILDREN

(a) **Girls:**

Small scale screening studies showed considerable evidence of behavioural deviance particularly in urban disadvantaged areas. Barton and Fitzgerald found that there was over twice as much behavioural deviance in 10 and 11 year old girls in a disadvantaged school as compared to a highly privileged school. It was also of interest that 21% of the children in the disadvantaged school were absent from school for trivial reasons, while none of the children in the privileged private school were absent for trivial reasons[25]. There is little doubt that children living in disadvantaged areas are under much greater psychosocial stress than children living in affluent and privileged urban areas. It is also likely that parents in privileged families have greater interest in education and would generally not have children absent from school for trivial reasons. It is clear that privileged families and privileged schools have more resources of both a financial or human kind which have the effect of reducing stress and behavioural problems in children.

(b) **Boys:**

A study of 10 and 11 year old boys in a disadvantaged school showed a similar behavioural rate to those shown by the girls in a previous study. 22% (10) of the boys with behavioural deviance showed evidence of mild abnormality, 4% (2) moderate abnormality and 9% (4) marked abnormality[26]. This supports the link between increased rates of behaviour problems and disadvantage.

(c)

A study of 2029 ten year old children found a rate of 20% behavioural deviance in boys and 11% in girls using the Teachers Questionnaire[27].

(d) **Urban : Rural differences:**

It was found that over twice as many urban disadvantaged children showed evidence of behavioural deviance as against children in a rural town. In the urban group no significant difference was found between boys and girls with behaviour problems while a highly significant sex difference was found in the rural small town group. The observed incidence for boys at 18% (21) was three times that found for girls[28]. The most likely explanation is that the level of psychosocial stress is lower in rural counties. There is little doubt that disadvantaged urban areas are increasingly psychologically toxic to families and children[28].

(e) **Travellers children:**

In a study of 50 travellers children 27 out of 50 showed evidence of behavioural deviance using the Teachers Questionnaire[29]. This was greater than that found when travellers children were compared to a comparison group from the settled community, the Teachers questionnaire total score average for the travellers group at 9.96 was significantly above the total score average for the settled comparison group at 2.2. While acknowledging that the travelling people have a different culture, it would appear that they are possibly the most disadvantaged group in Irish society and have large families with an unsettled, alienated life style which would make the increased rate of behaviour problems in children not surprising.

(f) **Depression:**

Five per cent (4) of a group of boys in an urban disadvantaged school scored as depressed on the Depression Self Rating Scale[30]. There was evidence of co-morbidity in that three quarters of those children who were rated as depressed also scored deviantly in the antisocial domain of the Teachers questionnaire. There was also a high negative level of self esteem using the Coopersmith self esteem inventory and depression[29]. A study of depressive symptomatology in Irish female adolescents found that in a rural area 22% showed evidence of it[31,32].

(g) **Anxiety:**

3.5% (3) of a group of boys in an urban disadvantaged school scored above two standard deviations above the mean for the state anxiety scale of Spielberger and 5% (4) scored more than two standard deviations on the trait anxiety scale of the same instrument and these were taken as being indicative of high anxiety. There was also a significant negative correlation coefficient between self esteem and state as well as trait anxiety[30]. Once again anxiety is not uncommon in normal school children and it is possible that strategies to boost self esteem by families and schools would be valuable particularly in the Irish context where negative attunement would appear to be a feature of the culture.

(h) **Autism:**

A study of prevalence of childhood autism found a rate of 4.3 autistic children per 10,000 in the age range 8 - 10 years in the Eastern Region Health Authority (formally the Eastern Health Board). These were evenly spread across the social classes and there was a male : female ratio of 1.3 : 1[33]. Parental personality differences were not found[34]. A study of sialyltranferase activity was found to be significantly increased in the serum of schizophrenic individually and unchanged in autistic serum[38]. Social support variables were important in relation to family burden and the person with autism[35,36,37].

(i) **Irish Childrens thoughts:**

15% of a sample of 80 boys thought that their life was not worth living most of the time and 18.8% thought that their life was not worth living sometimes[30]. A study of suicidal thoughts in children (N = 50) attending a child psychiatric outpatients found that 15% had

thought of killing themselves. 60% of the sample of children who had thoughts of killing themselves knew someone who had attempted suicide[39]. It would appear that very distressing thoughts are not uncommon and it behoves parents and teachers to tune into these thoughts in children so that they do not have to bear them alone and that the stress bringing them about should be identified.

(j) **Social difficulties:**

A study of 95, 11 and 12 year old school children in a normal school in a disadvantaged area found that 13% had difficulties with peers, 17% had difficulties with adults and 11% had general social difficulties using the Social Difficulty Questionnaire[40]. There is evidence that children with peer difficulties are at risk for later problems and it would appear that social skills training programmes in school could have preventive possibilities.

(k) **Sleep Problems:**

In a study of children attending a public health clinic (N = 101) with an average age of 4 years and 7 months twenty five per cent of the boys and thirty three per cent of the girls had sleep problems[41]. There is no doubt that sleep problems in childhood can cause very significant stress to a family. There are now simple behavioural programmes available which are particularly valuable for public health nurses and general practitioners in the management of sleep problems.

(l) **Reading:**

Children attending a child psychiatric outpatients had significantly lower reading ages than a matched age comparison group in a normal school - the mean reading age of the normal school children was 10.8 years while the group mean for the psychiatric outpatients was 9.0 years and the special school children 7.9 years[42]. While low reading age can occur without psychiatric problems it is not uncommon to see both occur together.

(m) **Fire Setting:**

A study of children attending a child psychiatric outpatients found that 19% (15) were fire setters. They set an average of 10 fires. The fire setting behaviour began on average at 7

years. Half of these children received a diagnosis of conduct disorder[43]. Fire setting behaviour can be the most serious of all childrens behaviour problems and it is important for doctors to ask about it as parents don't often mention it.

(n) **Childrens fears:**

40% of children attending a child psychiatric outpatients had evidence of excessive fears[44].

(o) **Obsessive Compulsive Disorder:**

A study of treatment approaches to O.C.D. in the 1990's suggest a multi modal treatment approach[45].

PRE-SCHOOL

A study in a pre-school (N = 59) found a rate of 17% of children with behavioural deviance using the Behaviour screening Questionnaire[46]. This is similar to rates found in other countries. These children are at risk for later problems and deserve intervention. Another study showed that psychiatrically distressed preschoolers showed poor performance in performing tasks or accepting limits[101].

ADOLESCENCE

(a) **Abnormal Eating Attitudes:**

Using the Eating Attitude Questionnaire 13% of a sample (N = 50) of 16 year old female adolescents showed evidence of abnormal eating attitudes. 11% admitted to dieting, 7% to exercising strenuously to burn off calories, 11% to avoiding foods with high carbohydrate content, 15% described eating binges with feelings of loss of control, 4% used laxatives, 17% felt that food controlled their lives and 18% admitted to feeling anxious in relation to eating[47]. Clearly food issues cause considerable distress and western societies excessive preoccupation with thinness is probably a factor in this problem.

(b) **Psychological Stress in Female Adolescents:**

A study found 7% to have admitted to being depressed[48].

Sex differences in psychopathology between male and female adolescents:

In a study of 92 adolescents (average age 13.8 years) it was found that in using the General Health Questionnaire that 44% of the sample reported six or more symptoms and there was no significant difference between males and females. On the other hand there was a significant difference between the mean scores for males and females, the females scoring significantly higher[49]. It is of interest that in child psychiatry that males have more psychological symptoms than females and here with adolescents there is no significant difference between males and females. Nevertheless the adult pattern is beginning to assert itself with females having higher mean scores than males. A study of the leisure activities of Irish adolescents found a high correlation between participation and interest[51,52]. The values[50] of adolescents reflected those of society at large.

Coping and Psychological Stress in Adolescence:

In this study it emerged that girls had more suicidal ideation than boys[53]. A problem solving intervention study for children with diabetes showed a positive response[54].

Body Shape, General Health and Abnormal Eating Attitudes in Male Adolescents:

Two out of 197, 16 year old boys showed evidence of abnormal eating attitudes. This was lower than a similar study in girls[47]. Thirty eight out of 197 boys showed 5 or more symptoms on the General Health Questionnaire. Three out of 107 boys showed excessive concern about being fat on the Body Shape Questionnaire[55].

Formal Psychiatric Disorder:

(a) A study of 45 10 and 11 year old children in a disadvantaged school found a rate of 18.6% (8). 7% (3) showed evidence of mixed order of conduct and emotions; 7% (3) showed depressive disorder and 5% (2) showed conduct disorder[25]. It demonstrated that about half those identified on screening questionnaires are false positives.

(b) A sample of 190 10 year old children selected from 2029 children screened for behavioural deviance found a rate of 16% showing evidence of formal child psychiatric disorder on detailed interviewing[27].

Psychiatric Symptoms in Parents:

(a) In a general practice study of 70 children there was a significant relationship between maternal depressive symptoms and behavioural deviance in the children[56].

(b) In a study of the mothers of 50 consecutive attenders at a child psychiatric outpatients 35 out of 50 showed evidence of formal psychiatric disorder using The Clinical Interview[57].

(c) In a pre-school study (N = 59) there was a significant relationship between depressive symptoms in mothers and behavioural deviance in children[58].

(d) When a consecutive sample of mothers with children attending the child psychiatric outpatients were compared with a comparison group of mothers of children attending a general practice significantly higher levels of hopelessness were found using The Hopelessness Scale[59].

(e) 72% of children of psychiatric inpatient mothers were found socially incompetent using the Child Behaviour Check List[60]. There was also a relationship between maternal depression and childhood behavioural problems[61,62].

Marital Disharmony:

(a) In a general practice study there was a significant relationship between marital disharmony and behavioural deviance in children[63].

(b) In a study of 50 consecutive children attending a child psychiatric outpatients 21 of the mothers showed evidence of marital problems and there was a significant relationship between marital problems and anxiety and depressive symptoms in the mother[57].

(c) When marital adjustment and behaviour problems in children attending a child psychiatric outpatients population were compared with a control population in the

community there were significantly higher rates of marital disharmony and behavioural problems in the children attending the child psychiatric outpatients[63]. It is important that general practitioners treat as soon as possible marital problems because of their effect on children. This is another example of preventive child psychiatry.

Social Problems:

Social problems of mothers were studied in 50 consecutive attenders at a child psychiatric outpatients. 74% of the mothers had significant social problems. There was a significant link between social problems and maternal mental illness in this study[57].

Home Environment:

When preschool children with behavioural problems were studied there was a significant relationship between low levels of warmth, affection and acceptance and a high score of behavioural deviance[64]. Clinical experience suggests that for children to develop healthily they need warmth, acceptance and affection but not over protection[61].

Bullying:

A study of 2000 children found that 4% of males and 1% of females were bullied[65].

Blood Lead:

In a study of blood lead in children attending a child psychiatric outpatients and in the community there was no difference in the mean blood lead levels[66]. Of course toxic blood lead levels would have major physical and psychological effects.

Adolescent Health:

In a study of adolescents health, 1% rated their health as poor. 25% drink alcohol at least once weekly and 29% had visited their G.P. in the previous three months. 61% had taken medicine in the previous four weeks. 16% of boys and 3% of girls had tried glue sniffing.

One quarter of Irish teenagers were weekly drinkers compared to one third of British teenagers[67].

Family Relationships:

A study of the Family System Test found it to be a poor predictor of clinical status[68]. Unfair, harsh discipline by parents was predictive of later development of depression[61].

Motivation:

It is of interest that children in an urban primary school show high intrinsic motivation to learning across 3rd to 6th standard. It was also of interest that behaviourally disturbed children showed higher levels of independent judgement as against dependence on teachers judgement. This may reflect a global mistrust of adults in their environment[69].

Feelings of misery in Two Thousand and Twenty Nine Children:

A study of 10 year old (N = 2000) children found that 2.0% of the males and 3% of the females were miserable[40].

Suicide and Parasuicide:

A study of suicide victims[70] in Dublin (N = 70) found that:

(a) 70% were males.

(b) Average age 41 years.

(c) 80% of victims under 55 years.

(d) 37% married.

(e) 60% of economically active group in employment.

(f) 35% previously attempted suicide.

Attitude to Authority:

In a study of attitude to authority in Irish adolescents 84% (76) expressed pro-authority feelings. There was also a negative correlation between level of psychological distress and positive attitude towards parents[47].

Life Events:

Children referred for psychiatric assessment had a significantly increased number of life events when compared to non-referred children from a normal school. Failure of a class in school and increased number of arguments between parents were associated with an increased likelihood of referral[87].

Psychoeducational Problems:

Males had significantly more behavioural and learning problems than females[88].

Child Psychiatry Provision:

It is clear that there is very considerable numbers of disturbed children in Ireland and there are still areas of the country without child psychiatrists. Educational psychologists should spend part of their week based in child guidance clinics so that psychiatric problems can be dealt with[89,90,91].

Prescribing in Child Psychiatry:

90% of Irish Child Psychiatrists prescribe psychotrophic drugs[92].

Child Psychiatric Inpatient Treatment:

The prevalence of use of medication was lowest (8%) in Denmark and highest in Ireland (54%). Family therapy was undertaken with 25% of inpatient cases in Ireland[93].

An Evaluation of a Child & Family Centre:

Significant improvement occurred in childrens behaviour with a 4% drop out rate[94,95].

Paediatric Outpatients:

82% of parents were satisfied with OPD services[96].

Preventive Psychiatry:

It is of critical importance to increase the priority given to preventive psychiatry and psychotherapy. The most cost effective time to intervene would be when children aged 3/4 years are showing signs of behavioural deviance. The children need high quality cognitively orientated preschool education and the mothers need parent training. There is a considerable need for the expansion of psychotherapy services in Ireland[97].

Family Burden of a Child with Special Needs:

When psychosocial stress in families with a child with special needs was compared to families with a child in a normal school it was found that there was significantly more stress in families with children with special needs. Parents in these families felt more incompetent, felt lack of attachment, were more restricted in their parent role, were more socially isolated, more depressed and had more marital stress. The child with special needs were more distractible, more moody, more demanding and more non-adaptible[98].

Prosocial Behaviour:

A study of prosocial behaviour in children attending a normal school found that Irish mean levels of prosocial levels of prosocial behaviour are similar to the United Kingdom mean scores. High trait anxiety was accompanied by lower prosocial behaviour scores and higher behavioural deviance ratings[99].

Self Esteem:

In a study of self esteem and behavioural deviance in children total self esteem was reduced in children attending the child psychiatric services. One component of total self esteem that is school self esteem was not reduced in children attending a day special school or were in an inpatient unit with a special school attached. This may have been due to children in the special school setting not being so different from each other as would be the case if these children were attending a normal school[98]. Preliminary results

suggest that parental self esteem and locus of control has an impact on childrens scores[100]. An inverse relationship was found between anxiety and self perception[100]. Disturbed preschool children were less competent at performing tasks[102].

Speech and Language:

In a study of speech/language disability and behavioural deviance in a consecutive sample of 50 referrals to a child psychiatric outpatients, 63% showed evidence of behavioural deviance on the Parents Questionnaire (A2) and 44% showed evidence of speech/language problems[103].

Temperament:

When a consecutive sample of children attending a child guidance clinic were age, sex and school matched with children in a normal school it was found that children attending the child guidance clinic were significantly more likely to have difficult temperaments[104].

Menarche:

The mean age of Menarche in 836 Irish school girls was 12.5 ± 0.06. There was no statistical difference between social classes, number of siblings or place of the child within the family[105].

Infant Care Practices:

When infant care practices were examined in mothers who had a child hospitalized and not hospitalized for gastroenteritis it emerged that families were the main source of advice for both groups. It was also of interest that 9% of hospital care mothers and 6% of home care mothers had no source of parenting advice. An average of 16% of mothers had problems feeding their children, 30% had settling problems at bedtime once per week or more and 35% had night wakening problems weekly. 22% of children posed some discipline problems. Most of the child care was provided by mother although fathers played with their children on average twice per week and mother three times per week[106].

Families of Ill Children:

The study also found an association between psychological stress and low levels of leisure activity, low levels of shared leisure with partners, poor overall contacts, poor satisfaction with contacts and a disturbed intra familial environment[107].

Diabetics with poor H_6 A_1 levels exhibited lower self esteem[108]. Twenty five per cent of mothers of diabetic children reported high levels of stress on the General Health Questionnaire[109]. A cognitive behavioural intervention significantly improved children with diabetes self efficacy[110].

Turner girls showed lower levels of self esteem and social interpersonal involvement[111,112].

Maternal Mental Health:

A study of maternal illness in 185 mothers showed a rate of 33% (61). 13 had endogenous depression, 16 anxiety / depression, 24 reactive depression, 3 abnormal grief, 3 alcoholism and 2 personality disorder. There was a significant association between parental mental illness and child psychiatric illness. 60% of mothers with parental mental illness had a child with child psychiatric illness. Mothers with mental illness had poor social relationships[113].

Antenatal Depressive Symptoms:

Fifty per cent of the women reported feelings of unhappiness and depression[114].

Impact of Hospital Experiences on Doctors:

The impact of hospital experiences during training of general practitioners were studied in relation to their propensity to admit children with gastroenteritis to hospital. There was a significant excess of hospital referrals for gastroenteritis by these GP's with prior hospital training in an infectious diseases hospital and medical sensitization was considered to be a factor in that this specialized training had sensitized GP's to the potentially negative outcomes of gastroenteritis[115].

Medication for Gastroenteritis:

25% of GP's are still using antidiarrhoeals and antiemetics in the treatment of gastroenteritis despite the general principle of fluids only for gastroenteritis[116].

Child Hospitalization:

In a study of home or hospital care for childhood gastroenteritis it was found that being either a young child, a child of a single parent or a child of an anxious mother were factors which were equally likely and more likely than being a moderately sick child to result in referral to hospital[117].

Pathways to Childhood Hospitalization:

The ability of parents to cope emerged as important factors in the hospitalization of children[116].

Immunization:

In a study of children who had gastroenteritis and were treated either in hospital or at home it was found that 53% of the home care children had measles immunization which is similar to national levels while only 22% of the hospital care children had measles immunization before 18 months of age. Levels of immunization up take were satisfactory for both groups in the early post natal period but began to decline and diverge at about the six month period. This fall off represents the age old problem of health education, how to maintain health orientated behaviours beyond a point of intensive contact, in this case the perinatal period[117].

Sudden Infant Death:

Considerable amounts of psychosocial distress was found in a national Irish study[118,119].

Attitude to Hospitalization:

While the evidence of negative impact of long or frequent hospitalizations of young children is well documented, a study of the attitudes of Irish doctors to hospitalization

found that only about half of those interviewed believed that hospitalization had negative effects, suggesting that research findings in this area do not appear to have had a major impact on the views of medical decision making[120,121].

Mothers Consumption of Drugs and Alcohol:

In a study of the consumption of alcohol and drugs in mothers of children attending a child psychiatric clinic it was found that 17% of the mothers were problem drinkers on a screening questionnaire - the Mast. 13% of the mothers were taking benzodiazepines daily while a further 7% were taking those drugs on an irregular basis. It is possible that these mothers are under more stress and have higher levels of problem drinking than women attending a general practice where a rate of 1.3% was found on a more sensitive screening instrument for alcohol problems the CAGE[122].

Fragile X Chromosome:

In the first Irish family studied with fragile X chromosome the proband with mental handicap and autism had on Cytogenetic study the fragile X in Tc 199 in 30 of his cells. His sister had fragile X chromosome in 25% of her cells and the younger sister had fragile X in 100% of her cells[123].

Delinquency:

In a review of the delinquency problem the principal of minimal intervention was evoked. The importance of scientifically evaluating all aspects of the legal, educational and health interventions in relation to delinquents was stressed. Institutional approaches have not generally been shown in effective and community approaches are probably least detrimental. There should be increased emphasis on high quality pre-school education as well as parent training and support for mothers of at risk children[124].

Disconnection and Disadvantage:

The issue of disconnection is particularly relevant to urban disadvantaged areas because socially isolated families are particularly at risk for psychological stress. Neighbours,

clergy, voluntary groups and professionals should try to make social links with isolated families. Social linkage and social support can make a significant impact on psychological distress. It is not surprising that people who have supportive confiding relationships are less at risk[125].

Mid Life:

The value and importance for the person in the middle years of linking with and guiding children and adolescents is generativity. This is particularly so for distressed children and adolescents who don't have anyone to take a positive interest in them as persons. A good experience of this nature for a child or adolescent may make the difference between success and failure in life[126].

Planning Skills:

In a study of children it was pointed out that there is no reason to suppose that crime is generally more common now than in past centuries. The importance of helping children develop planning skills and experience success is underestimated. It is important for parents and educators to build up childrens self esteem. Confident children are less at risk for psychological problems. Unfortunately negative attunement has been a feature of Irish child rearing[127].

Relational Model of Psychoanalysis:

It is important to realize that there was a shift in psychoanalytical thinking from Sigmund Freud's energy and economic models of psychological functioning to the relational psychoanalysis which emphasizes the importance of problems in relationships as factors in the development of psychological distress and disorders[128].

Cost Effectiveness of Psychotherapy:

Concern has recently been expressed that psychiatric educators may be "losing the mind". Brain science has not yet and probably never will fully explain the mind. There is little doubt that psychiatric training programmes do not give sufficient attention to

psychotherapy. A review of the literature concluded that the effect of psychotherapy was to reduce the use of medical services by about 20%[129,130]. There is evidence that psychotherapy is more effective than no treatment and has a greater effect size than placebo. A child psychiatric intervention showed effectiveness at 3 month follow up[131,132].

Supervision:

Insufficient attention has been paid to the supervisor/student relationship. If a supervisor is over concerned for the patient this suggests that the student is not tuned into the patient in an empathic way. If the supervisor is performing well then his comments should be confirmed by the patients material. The use of the student for narcissistic aggrandisement by the supervisors must be guarded against[133].

Technique of Psychoanalytic Psychotherapy:

The key elements of the technique of psychoanalytic psychotherapy are the analysis of the affect or pain that brings a patient and the analysis of the transference which allows the therapist to examine the forgotten feelings and attitudes developed in early life to important figures and transferred onto the therapist. These transference interpretations are most mutative that is, bring about the most change[134].

Applied Child Psychoanalysis:

Psychoanalysis has a role to play in helping paediatricians and nurses understand and respond to the emotional impact of physical illness on children. This aspect of intervention has tended to lag behind technology in the twentieth century. After the resolution of a medical crisis the psychological needs of children in the very stressful environment of the hospital situation are just as important in the long term as the physical care of the child. Psychoanalytical thinking has been of considerable assistance to lawyers and child care professionals in thinking about the best interests of the child and giving particular importance to psychological parenthood[135]. Multi-modal treatments have a place in treating patients with obsessional personalities.

A modification of the Anna Freud Diagnostic Profile has been made to make it quantitative[136]. The three models (a) Circumflex, (2) Beavers, (3) McMaster are not entirely satisfactory in differentiating clinical from non-clinical families[137].

Psychoanalysis, Behaviour Therapy and Pharmacology:

In the past the disputes between psychoanalysts, behavioural therapists and psychopharmacologists were very unsatisfactory and not in the best interests of patients. There is little doubt that these three forms of treatment have their place either singly or in combination. Psychopharmacological drugs tend to have as their focus symptom relief while psychoanalytic psychotherapy tends to show its effect more slowly and on background personality factors as well as symptoms. It may be more useful to view them as having an additive or even mutually potentiating relation. Behaviour therapy has a place in enuresis, encopresis and behaviour problems[138]. A study of the suitability of socially disadvantaged women found a significant number were suitable for psychoanalytic psychotherapy[139].

Balint Groups:

The Renaissance in General Practice, a phenomenon of the 1960's owed a great deal to the recognition of the enormous therapeutic potential in the doctor patient relationship. When problems occurred in this relationship it led to much unnecessary suffering, irritation and fruitless effort. Balint helped GP's to examine their countertransference feelings and to use these to increase their understanding of the neurotic problems of their patients which caused them and their patients so much suffering[140].

Pregnancy:

It is important to recognise mothers at psychological risk during pregnancy. Mothers with over valued pregnancies, ambivalent pregnancies and historical sensitization are at risk. It is a good time to intervene psychotherapeutically as mothers are highly motivated before birth and in touch with unconscious conflict and unresolved problems from childhood which may interfere with the psychological task of pregnancy which are emotional fusion with the foetus; differentiation of the foetus and self and progressive psychic separation of baby and mother[141].

Existentialism / Literature:

Existentialistic philosophy is helpful in understanding alienation and man in a technological world. There are problems with it in that it denies the whole concept of mental illness, the biological basis of some mental illness and also genetic factors. Existential psychiatry establishes a dependent relationship that gratifies but can not be worked through because the transference is ignored[142]. Literature is helpful to psychiatrists because they have similar concerns to poets and writers[143].

Hysterical Personality:

The patient with a hysterical personality thinks in a vague way with much feeling. This patient has difficulty in thinking clearly about feelings and behaviour. One of the aims of treatment is to help this patient to think clearly[144].

Narcissistic Personality:

Empathy is very important in treating the patient with a narcissistic personality disorder. These patients are further hurt by too painful interpretation early in the treatment. If the therapist is empathic the patient will experience a transmuting internalization which will be strengthening to the personality because a new internal object will be set up which will counter some of the negative internal objects from childhood[145].

Therapist Difficulties:

A study of a group of trainees conducting individual psychotherapy showed that the predominant categories of difficulty related to trainees feeling incompetent and threatened[146].

Registration of Psychotherapists:

There is a need now for a working party of the Department of Health to be set up to examine and draw up guidelines for the statutory registration of psychotherapists. The public is entitled to know the form, duration and quality of training that people who call

themselves psychotherapists and offer their services to the public have. This is particularly so because psychotherapy is not inert and has negative as well as positive effects[147].

Psychotherapy Services:

Psychotherapy services in Ireland are largely available in urban areas. The largest number of practitioners would be in the Eastern Region Health Authority area. In the public health service therapists are generally employed under their core professional titles i.e., psychiatrist, psychologist, social worker or nurse and often psychotherapy is one of a number of treatment strategies. At the same time there is a growing number of nurse therapists who undertake behaviour therapy within the psychiatric service[148,149,150].

Contribution of Psychoanalysis to Psychiatry:

The three theories most helpful in understanding mental illness are in the social domain, the biological domain and in the psychoanalytic domain. Psychoanalytic psychotherapy has a role in the treatment of patients particularly those with neurotic and personality problems. Psychoanalytic understanding is of assistance in management of a wider variety of psychiatric problems. It is very important for the clinician to be able to integrate psychoanalytic, biological and social understanding of the patient. While Kraeplin classified, Freud understood, both are required[151].

Psychotherapy in Custodial Institutions:

Psychotherapeutic experience has shown that is is possible to work psychotherapeutically in custodial institutions. Indeed some acting out patients are only available for treatment in a secure setting. The treatment is still a voluntary one in that the patient does not have to have the treatment if he does not wish[152].

Psychotherapy in a Psychiatric Outpatients:

A patient with neurotic depression failed to respond to antidepressants and hospitalization. It was only when childhood conflicts were dealt with in psychotherapy that they began to improve[153].

Psychotherapy Training of Doctors:

It is necessary for far greater emphasis and resources be given to training of psychiatrists in psychotherapy and for medical psychotherapists to have a place in the delivery of services to the mentally ill in Ireland[154].

Attitudes to Psychiatry:

Over the course of nurse training students become increasingly eclectic in their outlook and saw a place for ECT and compulsory detention of certain cases[155].

The Boundary of Psychotherapy:

There is considerable overlap between all the different forms of psychotherapy but also sharp differences that must be acknowledged. It is also critical that the limits of psychotherapy be acknowledged so that biological factors can be addressed by biological psychiatrists[156].

Oedipus Complex:

An unresolved Oedipus complex can cause serious parental disharmony[157].

European Psychotherapy and Counselling:

The 1988 Higher Education Diploma Directive had as its objective "the abolition of obstacles to freedom of movement for persons services and capital". In training terms the amount of professional experience may not exceed 4 years[158].

Future of Psychiatry:

An uncritical acceptance of Popperian empirical realism will lend to a marginalization of psychiatry[159 - 165].

Danger of Words[166]**:**

A great deal of confusion is caused in psychiatry by confusing discourses from different disciplines.

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