



MID-WESTERN HEALTH BOARD



REPORT OF WORKING PARTY ON SERVICES
FOR PERSONS WITH AUTISM

EASTERN HEALTH BOARD

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CHAPTER I

INTRODUCTION

1. In August, 1994 the Minister for Health published the report of his Department's advisor on mental handicap services for persons with autism. That report stated that "autism" is a condition first presenting itself in infancy and early childhood which is characterised by severe difficulties with communications, relationships and behaviour. It is associated to some degree with intellectual disability in the majority of affected children.
2. The exact prevalence of autism is open to debate. Depending on the diagnostic criteria being applied, up to 5 per 10,000 children manifest autism to a marked degree. A greater number of children may show much less symptoms, exhibiting an "autistic continuum" ranging from those who are mildly affected to those with severe disabilities. The prevalence rate for adult autism is not precisely known.
3. There is no single cause of autism, boys are more affected than girls in the ratio of 4 to 1. The condition manifests itself despite the absence of any obvious brain impairment or may occur in association with a variety of syndromes. Abnormalities are noticed by unresponsiveness, lack of interest, odd eating habits and fear of strangers. Early diagnosis is not easy, but is extremely important. Several diagnostic checks are now available, such as
 - the Childhood Autism Rating Scale (CARS),
 - the Autistic Behaviours Checklist (ABC), and
 - the Developmental Delay Behaviour Checklist (DDBC).

Early diagnosis allows suitable programmes to be implemented, and parents can be counselled on the management of the child who will exhibit disorders which have long-term implications.

4. **Summary of Recommendations of Department's Report on Autism:**
 - Regional diagnostic clinics should be established to provide a third-level diagnostic team and to act as a resource centre providing teaching programmes for staff in a variety of disciplines.
 - A range of school placement options is required depending on the needs of the individual child, the level of his/her mental handicap and taking geographical considerations into account.
 - A survey of existing pupils in schools for the emotionally disturbed should be carried out to ascertain the number of children with autism in such schools.
 - Special attention is required for adolescents with autism. Their needs during this period may greatly exceed those presenting at other times. Additional supports will be required to prevent crisis situations. Clear liaison and forward planning involving child psychiatric and mental handicap services is essential.

- Epidemiological studies regarding outcomes on autism should be given priority as a research topic with special emphasis on the relationship between treatment interventions in childhood and the resulting adult condition. Research on life expectancy is also required.
 - The adult with autism will require support and placement appropriate to his/her ultimate level of social adjustment and intellectual ability. The majority of adults with autism can benefit from facilities provided within the mental handicap services. A minority will need specialised units. Planned and existing residential places for this latter group are considered adequate for the moment.
 - Health Board plans for autism services should indicate the proposed timescale for implementation and cost implications.
 - Health Boards should prepare written protocols for staff on the management of children with autism.
 - Health Boards should establish a separate database on persons with autism in their areas.
5. The Chief Executive Officer set up a Working Party to consider how best the recommendations of the Report, as listed at paragraph 4 above, together with the views expressed on it by various bodies and interests in the Board's area, could be implemented. The membership of the Working Party is listed at Appendix I.
6. (a) The Working Party held its first meeting on the 13th February 1995 and met on 7 further occasions. A summary of its recommendations is set out in Chapter 2 below.
- (b) Written and oral submissions were received from those listed in Appendix II.
- (c) A sub-group of the Working Party held a meeting with Mr. Ger South and representatives of Parents of Children with Autism on 2nd May 1995 and discussed their submission on the development of services for persons with Autism.
7. The Working Party wishes to acknowledge its gratitude to the Irish Society for Autism and the Eastern Health Board for granting permission to quote extracts from their report "AUTISM". "A report of an Extensive Study of Persons with Autism in the area covered by the Eastern Health Board."

CHAPTER 2

SUMMARY OF MAIN RECOMMENDATIONS

- 2.1. A Pilot Project should be undertaken over an initial 2-year period to establish the true incidence and prevalence of autism within the Board's area.
- 2.2. A Regional Diagnostic & Advisory Team should be set up as a priority to assess all persons with the autistic spectrum.
- 2.3. The Daughters of Charity Service should take the key leadership role during the initial two year pilot phase.
- 2.4. Extra resources will need to be invested in providing more personnel for each service provider to enable a higher staffing ratio for autistic services. The number of extra staff required will be researched during the pilot phase period.
- 2.5. There is an urgent need to provide specialised training on Autism to all existing staff dealing with persons with autism, and parents/carers of such persons.
- 2.6. Community Support Services should be enhanced.
- 2.7. Special Classes in the Limerick City area should be set up as a priority.
- 2.8. A budget of £180,000 should be provided in 1996 to initiate the setting up of a comprehensive service during the two year pilot phase.

CHAPTER 3

A STUDY OF AUTISM IN IRELAND

3.1. In 1991/1992 the Irish Society for Autism in association with the Eastern Health Board carried out an extensive study of persons with Autism in the Eastern Health Board area. The authors of the study reviewed both national and international literature and research on the condition of Autism since it was first isolated as a condition of childhood development by Kanner in 1943. The following sections outline the main characteristics of Autism as outlined in the study.

3.2. The Syndrome of Autism

Over the last two decades our understanding of the nature and origin of autism has expanded greatly. In the sections below, the issues of diagnosis and definition, differential diagnosis, aetiology, and epidemiology of autism are discussed as well as the involvement of families and services in the world of the autistic person. A few points concerning autism should be made at the outset:

Firstly, autism is now viewed as a syndrome rather than a disease, a condition involving the presentation of a wide range of symptoms (in the domains of cognition, behaviour, communication and social interaction);

Secondly, autism is a developmental condition and a prolonged life-long handicap in the mode of mental handicap.

Thirdly, autism is not 'curable' by any treatments currently available and leads to a predictable pattern of social, cognitive and emotional dysfunction.

Fourthly, autism appears within a period spanning from birth to three years of age. Research does not throw light on the exact point at which autism appears. It is probable that parents may experience or notice some of the symptoms of autism during the first twelve months of the child's life.

The Third Edition of Diagnostic and Statistical Manual of Mental Disorders (Revised Version) (D.S.M. -III-R: The American Psychiatric Association, 1987) in its most recent form define autism according to deficits in three domains. These are the following:-

- A Reciprocal social interaction.
- B Verbal and non-verbal communication, imaginative activity
- C Repertoire of activities and interests.

3.3. Differential diagnosis:

The literature on autism and related disorders or disorders sharing some of the symptoms or features of autism has succeeded to a large measure in differentiating between autism and these conditions. The following are the disorders which are most frequently discussed in relation to autism:

- I Asperger's syndrome (e.g. Ehlers and Gillberg, 1993);
- II Childhood schizophrenia (e.g. Frith and Frith, 1991);
- III Mental retardation (e.g. Jacobson and Ackerman, 1990);
- IV Rett's syndrome (Olsson and Rett, 1987);
- V Language disorders (e.g. Bishop, 1989);
- VI Neuroses (Rutter, 1978);
- VII Disintegrative disorder (e.g. Kurita et al., 1992);
- VIII Other disorders and handicaps (e.g. Mayes et al., 1993).

3.4. Origin of Autism:

The question of the origin of autism has been answered in a number of manners. Kanner's early account of autism was not only the first to isolate the autistic condition as a separate clinical entity, it was also the first to implicate the family and more specifically the mother in the origin of the condition. Kanner's influence on subsequent views on the aetiology of autism should not be underestimated. Indeed, for several decades, the psychoanalytic model as originating in Kanner's work was the most widely accepted, indeed the only systematic account of the condition. Kanner is arguably the most significant figure in the history of thought on autism. Already mentioned for his description of 'infantile autism' and his belief that the disorder was emotional in nature, Kanner's approach to autism is most generally seen as residing firmly in the psychoanalytic tradition. Decades after Kanner's account of autism, interest in the early psychoanalytic views of autism continue to be of interest to authors, as is evident from the reviews of the psychoanalytic accounts which still appear in the literature (e.g., Haag, 1984).

Biological approaches to aetiology have been dominant in the literature in the last number of decades. The predominance of the biological hypothesis has led Gillberg (1990) to define autism as "a behavioural syndrome of multiple neurological injuries associated with a wide variety of medical conditions" (p.61). The picture created by research into the biology of autism has not presented a very clearly defined picture of what biological factors most strongly predispose to the development of autism. As Schopler (1987) points out, research has pointed to a number of different kinds of biological mechanisms as being involved in the aetiology of autism:

- (1) Genetic factors;
- (2) Infectious diseases;
- (3) Levels of uric acid;
- (4) Structural abnormalities;
- (5) Brain tumour;
- (6) Metabolic disease;
- (7) Viral insult; and
- (8) Poisoning.

The literature, particularly in the last number of years, has shown up a great number of factors which may be involved at some point in the aetiology of autism. Recent neurobiological studies have shown particular kinds of abnormalities among persons with autism: A widening of the fourth ventricle (Herold et al., 1988); A diminished brainstem (Gaffney et al., 1988); Hypoplasia of cerebellar vermal lobules 6 and 7 (Courchesne et al, 1988); Loss in Purkinje cells in the cerebellum (Ritvo et al, 1986);

Small P3 wave (Courchesne et al, 1985); Raised HVA levels (Gillberg and Svennerholm, 1987); High adrenaline and noradrenaline in plasma (Launay et al., 1987); Raised endorphin fraction II (Gillberg, 1989 a); and low beta-endorphins (Gillberg, 1989 b). These findings certainly suggest the importance of biological factors in the aetiology of autism, though they do not point to a single cause of the condition.

3.5. **Associated features of autism: social, cognitive, behavioural and communication:**

Outside of the diagnostic criteria for autism, the literature has confirmed a number of idiosyncrasies of persons with autism in each of the following overlapping domains:

I **Interpersonal and social activity:**

A number of idiosyncrasies have been found to characterise or at least to be more likely to appear in the interpersonal and social activity of persons with autism. As Volkmar (1987), among others, points out, social disabilities of persons with autism are among the most obvious and damaging aspects of this disorder. In general parlance, social behaviour comprises all of these activities that are concerned with the individual's interaction with others. Normal development generally involves the development over time of social skills which allow for reciprocal relationships between the subject and those in the environment. The person with autism operates within a very narrow field of social interaction. His behaviours are often judged to be socially inappropriate, so he tends to receive "special" attention from his peers and family. A form of limited interactional base results from the interaction of these two factors, the pre-existing autistic deficit and the social response to the subject's outputs due to this deficit. Boucher and Lewis (1992) obtained findings which suggest that persons with autism have a specific difficulty with facing recognition. As the authors indicate, this difficulty (whether it is primary or secondary in nature) contributes substantially to the social impairments among persons with autism. Capps et al. (1992) found that in terms of describing their emotions, autistic children exhibit difficulty in talking about emotions which are derived from involvement in society, emotions such as embarrassment and pride. Kasari et al. (1993) found that autistic children smiled upon finishing tasks with the same frequency as did mentally handicapped. They showed a lesser tendency to share their pleasure with parents and others around them.

II **Cognitive anomalies:**

A large number of authors over the last number of decades have asserted a belief that some form of cognitive deficits is apparent among persons with autism - that some deficit of a discrete or generalised nature is the basis for the autistic condition. Bartak et al. (1977) suggested that a cognitive deficit exists in autism. Baron-Cohen and his colleagues suggest that a cognitive deficit exists which prevents the development of a theory of mind in persons with autism. It is this deficit which is primary to this group. Rumsey et al. (1985) found that almost 75 per cent of persons with autism they examined were concrete in their thinking. Many individuals showed preservative and obsessional thinking. They found that none of the individuals were incoherent,

and though their speech was generally limited it was in all cases comprehensible. Olonoff et al (1991) found differences between autistic and normal control subjects in the theory of mind. Langdell (1978) suggests that the cognitive deficit underlying autism is one that specifically effects the processing of verbal and non-verbal information crucial to the conduct of interpersonal communications of any meaningful kind. Riguet et al. (1981) found diminished imitative capacity and symbolic functioning among children with autism (mean age = 10 years). Tager-Flusbert (1981) interpreted her results as indicating that a semantic cognitive deficit exists in persons with autism involving problems in the utilising of "conceptual knowledge about relational aspects of the environment". Among the more recent and interesting findings are the following: Ohta (1987) found that children with autism have an inability to acquire concepts of size, comparison and spatial relationship. Lincoln et al. (1988) found that mean Verbal I.Q. of the persons with autism they examined was two standard deviations below the mean while Performance I.Q. was only 1 standard deviation below the mean. The authors found that the difference between verbal and performance scores was highly significant.

III Behavioural idiosyncrasies:

The level of behaviour - concerning the overt activities, movements and actions of the autistic patient - has commanded some research in recent years. Adrien et al. (1987), for instance, found that nine particular behaviours distinguished autistic from non-autistic controls. These were finger flicking, body rocking, repetitive jumping, surface rubbing, social smile and laugh, eye contact, absent response to stimuli, using objects ritualistically and ignoring objects. In the area of differential attention to stimuli, Thaut (1987) found, among a number of less significant idiosyncrasies of such patterns of attention, that persons with autism spent significantly more time with a musical stimula compared to normal controls.

IV Communication difficulties:

Rumsey et al (1985) point to the wide range and number of language problems among autistic patients. This certainly does not point to very distinctive language deficits among persons with autism, and thus suggests that autism is not essentially a disorder of language. Language deficits are secondary. "Language status ranged from normal to concrete mutism. Impairments included very limited, dysphoric speech as well as highly deviant speech." (p.469). Howling (1987) comments on the limited range of babbling sounds of autistic infants as compared with those of normal infants and the parallel poverty in speech cadences which normally develop at a greater rate. Simmons and Baltaxe (1975) found that the most frequent "word use errors" found in persons with autism are those involving violations of semantic constraints. Tager-Fluishbert and Anderson (1991), investigating autistic children' communicative abilities, found that children with autism tend to be non-contingent rather than contingent in their use of utterances, when compared to a group of Downs Syndrome subjects matched for age and language level.

3.6. Epidemiology of autism

A number of major epidemiological studies have been carried out across the continents. These have revealed quite a lot concerning the epidemiology of the condition. The findings can best be summarised under a number of headings.

Prevalence:

The most general and perhaps most important epidemiological question is that of the absolute prevalence of the condition, the estimated number of individuals per 10,000 births as it is commonly defined operationally. A number of studies have provided estimates concerning the prevalence of autism in the general population. Broadly speaking, there has been a very wide range of estimates of the prevalence of autism the limits of this range being the .7 per 10,000 estimate of Treffert (1970) and the 13 per 10,000 estimate of Tanoue et al. (1988). Wing et al. (1976) found an estimated prevalence of 4.5 per 10,000. Ishii, and Takahashi (1983), in a Japanese study, found a prevalence rate of 1.6. Steinhausen et al. (1986), in Germany, in a community survey of autism, found a prevalence rate of 1.9 in 10,000 children under 15 years of age.

Sex Ratios:

From the outset of theorising on autism, the notion that sex differences existed in both the prevalence of autism and in the symptom profiles of individuals was considered. Indeed, among the 11 case histories described by Kanner in his seminal work on autism, there was a clear sex difference in the subjects involved (8 out the 11 were male). The research findings to date have supported the idea that such a gap in prevalence across the sexes exists. All studies have shown that there is an elevated rate of autism among boys. Bryson et al (1988) found a sex ratio of 2.5:1 in the incidence of autism between male and female subjects. Most studies have shown a ratio of between 1.4:1 and 3.4:1 (e.g. Steinhausen et al., 1986; Gillberg, 1984). A number of studies have shown ever higher ratios (e.g. those of Hoshino et al., 1982; Wing, 1981) where the ratios were 9:1 and greater. A number of authorities have found that this ratio increases with increasing I.Q., (Lotter, 1966; Wing, 1981); the higher I.Q. groups showing an even higher predominance of male over female cases. Most findings at present appear to be converging on an estimate of a 3:1 ratio of male to female cases. Those studies provide an account of the most widely cited findings concerning the ratio of male to female persons with autism. In Japan, Hoshino et al. (1980) found that males with autism outnumbered females with autism by a factor of 9. Two of the most recent epidemiological studies have been carried out in France (Fambonne and Mazaubrun, 1992; Cialdella and Mabelle, 1989). These studies agree on one important point. The male-female ratio in the prevalence of autism was found to be approximately 2:1 in the two studies. This contrasts very strongly with earlier findings which suggested a much higher ratio.

Socio Economic Status:

Early conceptions of the nature of autism contained wide references to the connection of autism to upper class well educated groups. Schopler et al. (1979) in a study carried

out in North Carolina in the U.S., found that this notion of increased incidence among upper middle class groups was unfounded. In this study, the researcher found that only 18% of persons with autism were from this category, 59% being classified as from the lower socio-economic level, and 23% from the middle class category. Steinhilber et al. (1986) found a slight predominance of middle class children diagnosed as autistic. Fombonne and Mazaubrun (1992) found that socio-economic distribution in the four French regions they examined did not significantly deviate from the census data available for these regions. Tanoue and Oda (1989) make the following observation: "Historical studies on infantile autism revealed that the disease developed more prevalently in the socio-economic status (SES) where the incidence of breast feeding was less frequent."

Race:

Epidemiological studies examining the distribution of cases of autism across racial groups have suggested that no pattern of increased susceptibility exists. In the North Carolina study (Schopler et al., 1979), researchers found that black and white groups were equally represented among cases (the proportion of cases from both groups reflected the overall proportions of the groups in the population from which the subjects were drawn).

Birth Order:

In relation to birth order, Kagan (1981) found that 94% of persons with autism examined had been the product of a first pregnancy. Krisnamurthy and Joshi (1987) found that 85% of cases of early infantile autism they sampled were either first or second born children. Jones and Szatmari (1988): "Suggests that following the birth of a seriously affected child, parents may decide not to have any more children or to have one more child and then no more" (p.31). Reinhard (1984) makes the following observation concerning his findings: "The youngest and oldest children in a family revealed a higher incidence of autism and hyperkinetic behaviour than did middle children".

Other Findings:

Hoshino et al. also found that while younger and older children were well represented with reported cases, there was a markedly diminished number of children in the middle age category. Parents of autistic Ss had significantly higher levels of education than parents of the control group, and 60% of the Ss' mothers had incidence of prenatal and perinatal complications". A number of studies have examined the differences between the symptom profiles of male and female persons with autism. Lord et al. (1982) for instance, found that males exhibited more advanced performances on eye hand integration and perceptual skills while also showing a higher frequency of unusual visual responses and stereotyped play patterns than female.

Geography:

In the past it had been suggested that Ireland showed higher rates of neuroses and psychoses and related conditions than average across Europe. This belief, however, has not been supported by research studies carried out over the last number of decades.

Previous Irish epidemiological studies in child psychiatry have shown rates of behaviour problems, psychiatric and determinants of psychiatric disorder to be similar to Western European rates.

3.7. The family and autism:

The literature to date suggests that a number of different kinds of factors impact upon levels of distress experienced by parents of persons with autism. These can be divided into a number of categories:

1. Stigmatisation

Though, as mentioned earlier, most theorists now believe that parents are in no sense culpable in the onset of autism, families of persons with autism still bear the pressures associated with a misunderstanding of the nature of autism - from the primitive attitude that autism is indicative of 'demonic possession' to the belief that families are responsible for the 'development' of autism. Cutler and Koxloff (1987) point out that "families with an autistic member have borne a degree of misunderstanding, blame, conflicting demands, devaluation and loneliness imposed upon them by society that typically exceeds that borne by other families".

11. Child characteristics

Gillbert (1991) points out that a very small, though not negligible, minority of autistic patients can lead relatively independent lives in the community, approximately two thirds continue to be dependent on others throughout the total developmental span. Beckman (1983), examining the influence of particular selected child characteristics on family stress, found that the following were strongly influential: responsiveness, temperament, repetitive behaviour patterns, and the presence of unusual care giving demands. Beckman also found that single mothers experience higher levels of stress than married mothers. Holroyd and McArthur (1976) using the Questionnaire on Resources and Stress (QRS: Holroyd, 1974), 1982) examined the levels of stress experienced by the mothers of persons with autism as compared to mothers of children with Down's Syndrome and outpatient psychiatric clinic children. The researchers found that mothers of persons with autism experience more stress than those of the other handicap grounds. In addition, they reported more disappointment with their child's development, the child's dependency, lack of services, the child's behavioural problems, and integration within the family, among other domains. However, findings in this area are not totally univocal. It appears that at a particular Developmental Quotient (DQ) level (approximately 65 and lower) the family experiences much more stress than when the DQ is above this level (Wishart et al., 1981).

III Structure of the family

Beckman (1983) found that single mothers reported more stress than mothers who lived with their husbands. Gill and Harris (1991) point to the buffering effects of social support and hardiness in the alleviation of stress among the

families of persons with autism. Harris (1988) emphasises how normal family stressors may be intensified by the fact of having an autistic child in the family. Having such a member leads to a restructuring of reality on the part of parents, and to a change in the pattern of reaction to what would have previously existed as minor sources of stress.

IV Epidemiological factors

The findings to date relating to the influence of age on perception of symptom severity has not been univocal. They have indeed at times been contradictory pointing to opposing trends. Some findings suggest that parents experience more stress when the autistic child is young than they do when the individual reaches adulthood, this presumably being due to the adaption of parents with time. Bebko et al. (1987) found on the other hand that parents find older children's symptoms less severe than those of young children. Bristol (1979) also found a higher level of stress was experienced by parents of older persons with autism than by mothers of younger children. This was true even though families in the younger and older groups did not differ in terms of socio-economic status, number of children in the family, hours of maternal employment, the children's mean I.Q. scores, or the adequacy of both formal and informal supports." (Bristol and Schopler, 1983, p.257). This clearly points to the importance of age as a variable in the determination of stress levels among mothers of individuals so handicapped. Bristol (1979) found that the kinds of stresses experienced by families varied with the age of the children while other studies have revealed that the specific problems experienced by parents vary with the age of the children (e.g. DeMyer, 1979).

CHAPTER 4

REVIEW OF EXISTING SERVICES

- 4.1. The main providers of services to persons with learning disabilities in this Board's area are:-
- (a) Brothers of Charity Services based at Bawnmore, Co. Limerick.
 - (b) Daughters of Charity Services, based at Lisnagry, Co. Limerick.
 - (c) Sisters of the Sacred Hearts of Jesus & Mary based at Roscrea, Co. Tipperary.
 - (d) Charleville and District Association for the Handicapped based at Charleville, Co. Cork.
- 4.2. These agencies provide a comprehensive range of services for designated geographic "catchment areas". The range of services includes the following:-
- Assessment and Counselling Services.
 - Day Care Services.
 - Special Schools/Special Classes.
 - Placement Services
 - Activation Units
 - Community Workshops.
 - Residential Centres.
 - Community Residences.
 - Home Support Services.
- 4.3. The Board also provides certain specific services throughout its area as follows:-
- Residential Accommodation in Psychiatric Hospitals.
 - Counselling Nurse Services in each Community Care Area.
 - Home Support Schemes in conjunction with the Home Help Service.
 - Community Paramedical Services.
- 4.4. Each Service Provider has been accommodating persons with autistic type behaviour within the mainstream services but does not have a specialist service geared to their individual needs. The lack of an appropriate specific service is considered to be a significant factor in contributing to various challenging behaviours in this client group.
- 4.5. The Department of Health's Report indicates a possible prevalence rate of up to 5 children per 10,000 who manifest autism to a marked degree. A greater number of children may show lesser symptoms and it has been suggested that the prevalence rate for this group may approach 20 per 10,000 children. For a variety of reasons the prevalence of adult autism is not precisely known.
- 4.6. The application of the Department of Health's suggested prevalence rate would indicate the following numbers of persons within the 0 to 19 age group:

	Census 1991	0-14 years	15-19 years
Limerick County	109,816	30,934	10,653
Limerick Co. Borough	52,040	12,468	5,590
County Clare	90,826	24,967	8,350
Co. Tipperary (N.R.)	57,829	15,767	5,405
TOTAL	310,511	84,136	29,998
Prevalence 5 per 10,000		42	15

An interpretation of the Department's prevalence rate would indicate that the number of new cases per year would be 2 to 3 in the Mid-West Region.

The Working Party considers that these figures under represent the true incidence/prevalence of Autism within the region.

- 4.7. In 1992, the Report of the Committee on Mental Handicap Services was adopted by the Board. A special feature of the Report was the provision of statistical data on some of the additional handicapping conditions which may accompany mental handicap. These conditions included persons with the autistic disorder syndrome. At that time 61 persons with moderate, severe and profound mental handicap were identified as also having the autistic disorder syndrome. At its first meeting the Working Party recommended that a Database be prepared which would show the numbers of persons with autistic disorder syndrome. The Board's Counselling Nurses for the Handicapped and the main Service Providers have since identified those persons within their services and in the community who exhibit the autistic disorder syndrome. The current database contains 113 such persons located as follows:

LOCATION	AGE DISTRIBUTION			TOTAL
	0-14	15-19	20+	
Community Care Area				
Limerick	27	6	26	59
Tipperary (N.R.)/ East Limerick.	11	9	9	29
Clare	16	4	5	25
TOTAL	54	19	40	113

- 4.8. As stated previously, there is no dedicated service for persons with autistic type behaviours. All such persons are accommodated within the mainstream Mental Handicap Services. Training for front line staff is provided on an "ad hoc" basis with

- no specific commitment to the provision of a comprehensive on-going training programme to meet changing needs.
- 4.9. There are no written protocols for staff on the management of children with Autism.
- 4.10. The Department of Education's position on childhood autism is set out in the Report of the Special Education Review Committee (1993). This Committee proposed seven principles which would serve as basic guidelines for the future development of educational services.

Principle 1:

All Children, including those with special educational needs, have a right to an appropriate education.

Principle 2:

The needs of the individual child should be the paramount consideration when decisions are being made concerning the provision of special education for that child.

Principle 3:

The parents of a child with special needs are entitled and should be enabled to play an active part in the decision-making process; their wishes should be taken into consideration when recommendations on special educational provision are being made.

Principle 4:

A continuum of services should be provided for children with special educational needs ranging from full-time education in ordinary classes with additional support as may be necessary, to full-time education in special schools.

Principle 5:

Except where individual circumstances make this impracticable, appropriate education for all children with all types of special education needs should be provided in ordinary schools.

Principle 6:

Only in exceptional circumstances should it be necessary for a child to live away from home in order to avail of an appropriate education.

Principle 7:

The State should provide adequate resources to ensure that children with special needs can have an education appropriate to their needs.

- 4.11. The central recommendation in the Special Education Report is that there should be a continuum of services to match the continuum of special needs. The continuum of services is about providing as wide a range of options as possible when placing pupils with special needs. The Report says that decisions on placement should be based on the assessed needs of the pupil, on the range of services available, on professional advice and on the preferences of the parents.

On the issue of integration, the view of the Committee is best summed up by saying that it favours "as much integration as is appropriate and as little segregation as is necessary".

- 4.12. It recommends that the following range of options should be available:-

- (a) Full-time placement in an ordinary class, without additional support.
- (b) Full-time placement in an ordinary class, with additional support in the class.
- (c) Full-time placement in an ordinary class but with withdrawal for short, regular tutorial sessions.
- (d) Part-time placement in a special class, spending more time in the ordinary class.
- (e) Part-time placement in a special class, spending less time in the ordinary class.
- (f) Full-time placement in a special class.
- (g) Part-time placement in a special school, spending more time in the ordinary school.
- (h) Part-time placement in a special school, spending less time in the ordinary school.
- (i) Full-time placement in a day special school.
- (j) Full-time placement in a 5-day residential special school.
- (k) Full-time placement in a 7-day residential special school.
- (l) Part-time placement in a Child Education and Development Centre and part-time in a special school.

- 4.13. The range of options outlined above has considerable implications for the system as a whole and for the Department of Education in particular. It implies, for example, that there should be:

- additional resource in the ordinary schools, mainly in the form of smaller classes
- more remedial teachers in ordinary schools

- more resource teachers and/or visiting teachers
- more special classes
- better resources in special schools including smaller classes.

4.14. Equally important are the implications that there should be more contact and interchange between special and ordinary schools and the possibility for pupils of movement from one service to the other (i.e. not just a one-way traffic) for appropriate lengths of time depending on the pupils' needs.

It also highlights the fact that there is scope for considerable progress in the development of services in designated ordinary schools, both at primary and second level, so that pupils with special needs can be located in a school in which additional resources are made available to cater for their needs.

4.15. At present, educational services for children with autistic type behaviour are provided either in special schools or special classes. There is no dedicated service within the Mid-West Region and the individual needs of such children are not being adequately met. There are no children presently placed in the normal mainstream school system.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS OF WORKING PARTY

5.1. In reviewing the recommendations of the Department of Health's Report, the Working Party at its first meeting endorsed and adopted the three general principles which should underpin the treatment of persons with Autism:-

- Where possible the child should be treated and educated in the same setting as all other children i.e. in mainstream services. The recent expansion in community based play groups and day care services for pre-school children should facilitate this objective.
- Where mainstreaming is not possible, specialised services should be provided.
- For either option those involved in the child's or adult's education should have an awareness of the special nature of autism and should have the training to deal with the special demands it presents. Support from a variety of Consultants should be readily available to staff as required.

It is also recommended that particular action be taken over an initial pilot period of 2 years which would see the setting up of a Regional Diagnostic and Advisory Service to assess all persons with the autistic spectrum. Any staff attached to the service after the pilot period would either continue on the service, or be assigned to other duties depending on the outcomes of the project.

5.2. As a result of

- (a) reviewing the Department's recommendations,
- (b) reviewing the services presently available within the Region and
- (c) considering the written and oral submissions made to it (see Appendix II)

the Working Party proposes the following which will lead to the provision of a comprehensive service for persons with Autism in the Board's area.

- One Regional Diagnostic & Advisory Team should be set up as a priority. The Team should comprise a core group of:
 - Consultant Paediatrician
 - Consultant Child Psychiatrist
 - Senior Psychologist
 - Senior Speech and Language Therapist
 - Other personnel such as a Genetic Counsellor, Dietitian, Community Nurses, as appropriate,

and will participate on the Team as part of their normal functions.

- In providing the necessary quality and level of services the Assessment Team will require time and resources to develop their own skills and expertise in addition to their clinical work.
- 5.3. The Working Party proposes that the Daughters of Charity Service should take the key leadership role in developing services during the initial two year pilot phase. The posts of Senior Psychologist and Senior Speech & Language Therapist will be assigned to their service for this specific purpose.
- 5.4. Initially one Regional Diagnostic & Advisory Team should be established but the Working Party considers that there may be a need to develop one Team for each Community Care area following the initial 2 year pilot phase. The diagnosis of Autism should be made only by the Assessment Team. Diagnostic Assessments will be ongoing and observations will be made as far as possible in the natural environment i.e. the home. The Role of the Team will also include the identification of the support needs of families and the appropriate educational services. An ongoing evaluation and review of role and functions of the Team will be carried out.
- 5.5. The Working Party considers that at this stage extra resources should be invested in providing more personnel for each service to enable a higher staffing ratio for treating persons with autism rather than the provision of a special residential centre or special unit.
- 5.6. The Working Party considers that there is an urgent need to provide special training in Autism for all existing staff dealing with persons with the autistic syndrome. (Appendix IV outlines a training programme.) As an immediate step, the Working Party recommends that a Workshop/Seminar on an appropriate training programme should be arranged for all professional staff, including teachers, within the Board's area. One person within each service should be designated to monitor the implementation of the training programme.
- 5.7. The Working Party recommends that Community Support Services should be provided as a priority. These would include the provision of a Respite Care Service and a special Fostering Scheme. The three Counselling Nurses should play a lead role in developing these services.
- 5.8. The Working Party welcomes the decision of the Minister of Education to introduce a pilot programme of special educational support services for children with Autism.

This programme will involve:

- (a) The allocation of extra teachers to specifically address the educational needs of children with Autism.
- (b) The delivery of specially tailored education programmes to meet the needs of these children.
- (c) The delivery of special in-service support to the teachers concerned. (Appendix V).

- 5.9. The Working Party recommends, and supports, the setting up of a Special Class in the Limerick City area as a pilot project. The Working Party also recommends that the Department of Health should fund the post of Child Care Assistant for the Special Class during the pilot phase. Funding should also be made available to ensure that the necessary transport arrangements, including the provision of escort(s), are put in place to enable the Special Class to proceed.
- 5.10. It is envisaged that this Special Class will be the initial focus of assessment and intervention by the Regional Diagnostic & Advisory Team and that the experiences gained will be utilised to further the development of services elsewhere in the region. The Working Party considers that the need for similar special classes in other locations should be researched as soon as possible.
- 5.11. The Working Party recommends that a Research Project be undertaken to establish the true incidence and prevalence of the autistic disorder syndrome within the Board's area.
- 5.12. The Working Party discussed a number of models of service delivery and suggests the proposed model in Appendix VI. It has been recommended that a multidisciplinary Diagnostic and Advisory Team be established for the region initially. Following this as needs become apparent, a core team of specialised staff should be established to support people with autism and their families at home and in appropriate pre-school and school services. It is envisaged that this specialist support team would also liaise with existing service providers in the region. This team should be comprised of multidisciplinary staff and should operate an outreach function.
- 5.13. The Working Party considers that all professionals dealing with persons with Autism should have access to up-to-date information in the following areas:
1. Research into possible causes.
 2. Understanding Autism as a spectrum of disorder.
 3. Underlying care problems.
 4. Management approaches within Ireland and abroad.
- 5.14. The Working Party recommends that it should continue as a liaison group to monitor the setting up of appropriate services to meet the needs of persons with autism in the Mid-West Region.

APPENDIX 1

MEMBERSHIP OF THE WORKING PARTY

- Mr. M. J. Duffy, Asst. Chief Executive Officer (CHAIRMAN)
Dr. M. O'Mahony, A/D.C.C.M.O.H., Limerick
Dr. J. Ledwith, Consultant Psychiatrist, Bawnmore Services, Limerick
Dr. M. Mc Loughlin, Consultant Psychiatrist, Our Lady's Hospital, Ennis.
Ms. M. Ryan, Counselling Nurse for the Handicapped, Limerick.
Ms. D. Taylor, Senior Psychologist, Lisnagry, Limerick.
Ms. M. O'Halloran, Nurse Behavioural Therapist, Bawnmore, Limerick
Sr. S. Ryan, Director of Services, Lisnagry, Limerick.
Dr. E. Robertson, Senior Psychologist, St. Anne's Centre, Roscrea.
Ms. A. Halliday, Snr. Psychologist, Brothers of Charity Services, Co. Clare.
Dr. L. Carroll, Consultant Paediatrician, Regional Hospital, Limerick.
Ms. M. Foley, Speech & Language Therapist, Daughters of Charity, Lisnagry.
Ms. D. Ryan, Community Care Coordinator, St. Anne's, Roscrea.
Dr. N. Adamson, Consultant Child Psychiatrist, Regional Hospital, Limerick.
Mr. B. Murphy, Senior Inspector, Dept. of Education, Cork.
Mr. P. A. Sheehan, Senior Executive Officer (SECRETARY)

APPENDIX II

WRITTEN AND ORAL SUBMISSIONS

The Report "Services for Persons with Autism" was given wide circulation both by the Department of Health and by the Mid-Western Health Board. Following this, submissions were received from the following:-

1. Dr. T. Fitzpatrick, former Director of Community Care, Clare.
2. Dr. M. O'Mahoney, A/Director of Community Care, Limerick.
3. Dr. M O'Mahony-Toohey, A/Director of Community Care, Tipperary (N.R.)/East Limerick.
4. Dr. P. Kirwan, A/Chief Psychiatrist, St. Joseph's Hospital, Limerick.
5. Dr. M.J. Ledwith, Consultant Psychiatrist, Bawnmore Services, Limerick.
6. Dr. M. M. Hayes, Consultant Psychiatrist, Bawnmore Services, Limerick.
7. Ms. Maud Ryan, Counselling Nurse for the Handicapped, Limerick.
8. Ms. Margaret McNamara, Counselling Nurse for the Handicapped, Clare.
9. Ms. Emer Carroll, Counselling Nurse for the Handicapped, Tipperary (N.R.)/East Limerick.
10. Br. John O'Shea, Director of Services, Bawnmore, Limerick.
11. Mr. David Kieran, Director of Residential/Community Care Services, St. Anne's Roscrea, Co. Tipperary.
12. Sr. Sheila Ryan, Administrator, St. Vincent's Centre, Lisnagry.
13. Mr. Ger South, Limerick Parents & Friend Association of the Mentally Handicapped.
14. Ms. Margot Olden, Guardian Angel Pre-School, Thurles, Co. Tipperary.
15. Ms. Mary Powell, Thurles Workshop Trust, Thurles, Co. Tipperary.
16. Mr. & Mrs. Jeffrey & Elizabeth Greenwood, Cratloe, Co. Clare.
17. Mr. & Mrs. Noel & Breeda McCloskey, 42 Silverbrook, Mill Road, Corbally.

The main recommendations made in the submissions were:-

1. A multi-disciplinary Assessment/Diagnostic Team should be established.
2. Provision of Respite Care, Home Support and Crisis Intervention Services for persons with Autism.
3. Provision of support services for families of children with Autism.
4. Provision of an appropriate educational service including Pre-Schools.
5. A Residential Centre or Units for children and adults to be considered.

APPENDIX III

ESTIMATED 1ST YEAR COSTS OF THE PILOT PROJECT

Salaries:

Senior Psychologist	£35,000	
Senior Speech & Language Therapist	£25,000	
Consultant Sessional Fees	£20,000	
Classroom Assistant	£15,000	
Home Support Services	£20,000	
Secretary	<u>£15,000</u>	£130,000

Non Pay Costs:

Training	£5,000	
Office Accommodation	£11,000	
Travel Expenses	£10,000	
Assessment Equipment	£10,000	
Office Equipment	£10,000	
Miscellaneous	<u>£4,000</u>	<u>£50,000</u>

TOTAL **£180,000**

APPENDIX IV

TRAINING

Staff of Psychiatric Units in charge of persons with Mental Handicap, including Autism, should have the same Training as those who are dealing with Mental Handicap in other areas of the Health Board and related agencies for e.g. Bawnmore, Lisnagry, Roscrea etc. In particular, staff who are prepared to work in developing community services for those with Mental Handicap ie. Kilrush and Limerick, should be released for special training on Autism.

Staff would require the following Training:

- MODULE 1. Diagnosis of Childhood Autism - including Autistic Continuum and Asperger's Syndrome. This module could include possible Causes and Differential Diagnosis. Liaison with Special Diagnostic Team in the Mid-West would be beneficial.
- MODULE 2. Treatment and Management of childhood autism including infancy and pre-school, early school, and adolescence. Networking with staff in the field of education, staff in workshops, residential centres and respite care should be included. Attention to Family Therapy should be provided.
- MODULE 3. Diagnostic Indicators in young adulthood/old age Autism. With more emphasis on Autism in later life, this module could include a Research Project which could enable staff in Psychiatric Hospitals and Developing Community Services to detect more precisely prognosis in those with Adult Autism.

Educational, social, recreational and residential needs of middle aged/elderly Autistic should be stressed. In this module, visiting speakers from centres of excellence could be invited to speak.

When planning in the Mid-West is under way it is important that resources such as staff and facilities are in place not just for the child but all through the life of the person with Autism.

APPENDIX V

FREAGRA ON T-AIRE OIDEACHAIS RE EDUCATIONAL SERVICES FOR CHILDREN WITH AUTISM

I propose to introduce a pilot programme of special support services for children with autism. This programme will involve:

- the allocation of extra teachers to specifically address the educational needs of children with autism.
- the delivery of specially tailored education programmes to meet the needs of these children.
- the delivery of special in-service support to the teachers concerned.

It is intended that this pilot programme will be tested in a number of selected locations over the coming year. The programme will be monitored and the experience gained will provide a valuable basis for the development of a longer-term response in this area.

The areas being selected for the pilot phase of the programme are those where numbers of children with autism have been identified.

In the case of each location chosen, the intention would be that the arrangements put in place would be developed in close consultation with the authorities of the schools concerned and the relevant health authorities.

In some cases, for example where the children attending a school are predominantly in the autistic group, the response will be "whole school" based. In other cases, the number of children involved or their particular requirements may suggest that the provision of a separate class or unit might be more appropriate. There is a need to be flexible and to allow for the development of approaches which best suit the needs of the children concerned.

I am aware of the demands from representatives of the autistic children for the provision of dedicated facilities to meet their educational needs. However, given the variety of difficulties which can attach to autism, I am anxious that any steps taken in this area will be of maximum benefit to the children concerned. Experience gained with the pilot programme will have value in this regard.

My officials are currently in discussion with the Autistic Society in regard to the pilot programme and I hope to make an announcement in this connection in the near future.

I am aware of the programme in Northern Ireland to which Deputy refers. I understand that this programme is also operating on a pilot basis at present and my Department will be interested in learning the outcome of that initiative in due course.

PROJECTED SERVICE MODEL

Primary Referral Sources

Awareness & Education

Early Diagnosis

- Paediatricians
- Area Medical Officers
- Public Health Nurses
- General Practitioners
- Others

Early Childhood Services

- Home based parent support training
- Supported pre-school placements
- Information and counselling
- Parent and sibling groups
- Family Support
- Local Respite Relief
- Individual Programming
- Regular Review
- Link with school services

Adult Services

- Residential Service
- Day Service
- Home Support Service
- Respite Care Service
- Information/Counselling

- Paediatrics
- Child Psychiatry
- Clinical Educational Psychology
- Speech & Language Therapy
- Family Support Work
- Dietetic Service
- Genetic Counselling

DIAGNOSIS

REFERRAL

Diagnostic & Advisory Team

Specialist Team Support

School Service

- Supported Placements in Mainstream
- Special School
- Individual Programming
- Regular Reviews
- Family Support
- Local Residential Relief and placement
- Information & Counselling
- Parent and sibling groups
- Link to adult services

