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DOWN'S SYNDROME IN GREEK CHILDREN: FIVE CASE STUDIES ON CHILD AND FAMILY BACKGROUND

I. INTRODUCTION

Down's syndrome (DS) (mongolism) is the most widely known chromosome abnormality. Children with this anomaly have three number 21 chromosomes instead of the normal two. Hence, the condition is also called «trisomy 21». However, DS can also be caused by a number of other chromosome abnormalites. Down's syndrome has been recognized as a distinct clinical entity and as causal mental retardation (MR) since the latter half of the ninenteeth century (Down 1866). The plausible explanation for its late recognition as a distinct entity is that DS child was confused with the dwarfed and mentally deficient cretin (Volpe 1986). A review of the literature that has compared mongoloid and nonmongoloid retarded subjects on behavioral tasks indicates that while there appeared to be more similarities than differences between these two groups several problems arise in drawing firm conclusions from the studies (Johnson and Olley 1971). The behavioral differences between mongoloid and nonmongoloid subjects are a function of psychological, not medical, differences (Birch and Demb 1959, Hemerlin 1964).

Because it has been recognized for so long, DS has been very extensively researched. Investigators coming from different disciplines such as medicine, psychology, education, sociology etc. have studied DS related issues. They have found that people afflicted with mongolism suffer from a variety of developmental, biochemical and

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* This article, is based on the author's paper presented at the 4th International Down Syndrome Convention, Jerusalem, Israel, March 19-24, 1989. Its introductory review of the relative bibliography was enriched with recent research data on Down's syndrome in children and youth.

clinical abnormalities, among which is a greatly increased susceptibility to inflectious diseases, especially of the upper respiratory tract (Benda 1960).

In the present study we shall try first to make a review of the existed international and Greek bibliography related to the Down's syndrome in children and youth and then to report and discuss five cases of DS children living in two towns, Ioannina and Egoumenitsa, located in the North-Western part (called Epirus) of Greece.

In numerous biochemical investigations subjects with DS have particularly been demonstrated to have an elevated amount of gamma-globulius in the serum of these individuals (Appleton and Pritham 1963, Fluck and Pritham 1964-65), a chromosome aberration being possibly antecedent to different biochemical mechanisms (Pozsonyi and Gibson 1965-66), an abnormal serotonin metabolism (Keel et al. 1969), a molecular based chromosome behavior during their cell division (Smith and Warren 1985) and frequent EEG abnormalities (Ellington, Menolascino and Eisen 1969). It is noted that over 90 percent of those fetuses with chromosome errors are spontaneously aborted (Holmes and co-workers 1972). The chromosomal disorder is common to about 95 percent of all cases of DS. There are many possible causes of chromosomal aberrations including radiation, drugs, viruses, and gene mutations. There is also evidence (Ganiban, Wagner, and Cicchetti, 1991) of abnormalities in the postnatal growth and elaboration of neuronal networks, as measured by the growth and structure of dendrites and extensions of neurons. This decreased maturation may account, among others, for the difficulty in synthesizing information quickly and efficiently. It may also underlie an inherent decrease in reactivity to stimulation. The one factor most highly correlated with DS births is maternal age (Smith and Wilson 1973). The odds that a woman over age 45 will give birth to a DS child are 20 times greater than that of a woman under age 30. In fact, the odds increase very rapidly at ages over 30 (Pasamanick and Lilienfield 1955, Smith and Wilson 1973) (see Table 1 below).

In regard to the relationship between the age of the mother and the number of mongoloid births a slightly different picture had been presented by Knobloch and Pasamanic (1962), and Robinson and Robinson (1965) (see Table 2 below).

TABLE 1

The relationship of Down's syndrome to maternal age

Maternal age	Frequency of occurence
<30	1:1500
30-34	1: 750
35-39	1: 280
40-44	1: 130
> 45	1: 65

Source: Smith and Wilson (1973), p. 17.

TABLE 2

The relationship between the age of the mother and the number of mongoloid births

Mother's age	Frequency of occurence
15-24	1: 1500
25-34	1: 1000
> 35	1: 150
40-44	1: 70
> 45	1: 38

Sources: Knobloch and Pasamanic (1962), Robinson and Robinson (1965).

The main findings of clinical investigations in DS children suggest that trisomy and translocation subtypes of mongolism display differences in clinical, dermatoglyphic, morphological, psychiatric and behavioural status (Gibson and Pozsonyi 1965). The stereotype of children with DS is that they are frendly, sociable, and open. However, research on sociability has only partially supported this picture (Hodapp and Zigler 1991; Serafica 1991). It should be noted, at this point, that intellectual level and adaptation are undoubtedly related; however, the correlation between these two constructs is not so high that the latter can accurately be inferred from the former. In certain instances the correlation may be low (Wenar 1994). The interesting thing is that retarded individuals with mongolism, as a group, tend to exhibit less maladaptive behavior than retarded without mongolism (Moore, Thuline and Capes 1968). Mongoloids show greater social competence (while they do appear to have a special problem in communicating to others), as measured in terms of frequency with which they are capable of certain adaptive behaviors, than do nonmongoloids (Johnson and Abelson 1969). By using simple behavior modification techniques disruptive classroom behaviors of DS children do decline, other equally inappropriate behaviors of those individuals also decrease while teacher's behavior that may have undesirable effects on the children are also modified (Romero 1985). Down and nondelayed infants appear to organize their exploratory behavior (i.e. to explore the inanimate environment) in a similar fashion while, rather, vary considerably in the distribution of behavior (the major differences between the two groups revolve around the transitions to and from looking which may indicate that the psychological meaning of looking may be different for the two groups (MacTurk et al. 1985). The ability of DS children to solve different kinds of mirror tasks parallels that of normally developing children, but motivational, attentional and exploratory differences may exist (Loveland 1987). Some clinical aspects of mongolism are generalized hypotonia, psychiatric disorders, abnormal EEG, hearing loss etc. (Mclntire, Menolascino and Wiley 1964-65).

The psychological literature contains numerous investigations of mongolism which have shown that mongoloids are significantly inferior to familial retardates in learning abilities (Martin and Blum 1961). A number of studies have reported contradictory evidence on the relationship of physical stigmata to intellectual status in mongoloids. Some investigators have reported a significant positive re-

lationship between frequency of stigmata and *amentia* in mongolism (Gibson and Gibbons 1958) while others have presented negative evidence (Dunsdom, Carter and Huntley 1964-65, Shipe et al. 1967-68). However, according to Baumeister and Williams (1967) who have reviewed a number of studies in this area, the majority of such studies have failed to demonstrate any systematic relationship between number of physical stigmata of DS and the degree of intellectual deficit associated with this condition. The highest IQs were found in the cases of children with mosaic chromosome pattern (Shipe et al. 1967-68).

A longitudinal study of mongol babies reared at home or placed in foster homes and institutions reveals that the mongol children are significantly below the controls on their mental and motor development (Carr 1970). The decline in intelligence in DS children begins in infancy and proceeds at a decelerated rate thereafter. While some chidren may have average intelligence, the mean IQ of the group as a whole is around 50. The reason for this decelerated pattern is unknown (Hodapp and Zigler, 1991). There is also evidence for increased mental capacity with age in Down's syndrome cases. Results of a study show that 2/3 of the 15-17 years old DS subjects could perform tasks which no 6-8 years old could, suggesting that they might benefit from educational experiences which were of no value at a younger age (Sinson and Wetherick 1976). Also an exploratory study examining the use of the ITPA in DS children shows that the subjects respond to it in what appeared to be a consistent cognitive style. In that study the development of educational programmes appropriate to these results is encouraged (Bilovsky and Share 1965-66). The structure of intelligence in children with DS does not resemble that of normally developing children. In normal development various cognitive skills are at more or less comparable levels, while in DS development is disjointed. Thus, social skills are in advance of general intelligence or, again, the purely cognitive aspects of language such as syntax may lag behind the social aspects of pragmatics. The reasons for such disjointed development are not understood (Hodapp and Zigler, 1991). Findings of a summary of the past decade research into the development of children with DS show that those individuals experience delays as a result of both physical and cognitive problems, although with an appropriate stimulating environment, it is not until the DS child reaches school age that the previous delays cause problems serious enough to necessi-

tate intensive training. The major problem for DS children appears to be an inability to handle more advanced cognitive strategies. Parents prove to be able to stimulate and encourage their DS children in all aspects of growth and development (Hartley 1986).

In regard to *specific* aspects of cognition in young DS children, most evidence points to problems in memory and attention being responsible for their subnormal performance compared with their normal peers.

Several theories have been proposed to explain cognitive deficits with emphasis on memory deficits. Broadbent's (1958) *limited buffer theory* suggests that such individuals, within the framework of mental retardation, have a smaller capacity to store information, and that the addition of new information requires the purging of «old» information. Slamecka (1968) in his elaboration of the *bottleneck theory* proposed by Tulving (1968), asserted that memory is impaired by the ability of the child to retrieve information and not by a limited storage capacity. This theory is supported by the superiority of our recognition memory skills over our recall skills.

When comparing recognition memory of normal and DS children, Down children still show significant delays consistent with general developmental lag (Fanz, Fagan, & Miranda, 1975). McDade and Adler (1980) further extended the investigation of this problem by comparing visual and auditory memory skills in preschool age DS children. Their findings revealed limitations in the storage and retrieval of auditory information and severe impairment in the storage of visual information. The differential memory for visual and auditory information was consistent with other findings for young children (Rohwer, 1970). Generally speaking, language conforms to the developmental model of delay without deviance, although all aspects cannot be reduced to that simple formula (Fowler, 1991). Researchers agree that the language of DS children develops in the same sequence as does the language of nonretarded children. However, DS children experience delay in the acquisition of language (speech) relative to intellectual, social, and motor development, which may be caused by factors such as auditory deficiences, articulation disorders, or problems with the concept of object identity and object performance (i.e. with the verbal communication skills (Pruess Vadacy, and Fewell 1987).

A study on receptive and expressive language skills of DS children has shown that 1) the language development of severely

retarded mongoloid children (with IQ as low as 32) suffers most; 2) they can be taught to read and comprehend what they are reading without a prohibitive amount of time, energy and expense; and 3) in providing an enrichment programme, expectations should be high (Rhodes et al. 1969). Two other studies examining the effect of sentence complexity on the ability of trainable mentally retarded DS children to comprehend and imitate verbally presented sentences have revealed that subjects comprehend simple declarative sentences significantly more often than chance expectancy, but comprehend negative sentences less often than would be expected by chance. Imitation of simple declarative sentences (obligatory transformations only) is significantly better than imitation of sentences in which optional tranformations are applied (Semmel and Dolley 1971). Results of studies concerning the phonological system of mental age matched, normal, severely subnormal and DS children indicate that phonological development is linked to general mental development in severely subnormal non- DS children. Mongoloid subjects make more phonological errors and those errors are more inconsistent than errors by the two groups (Dodd 1976). A study on early vocabulary acquisition by children with DS has shown that those individuals are at the same level of cognitive development as the nonretarded subjects at the onset of both comprehension and production of object names. Soon after language acquisition begins however the language development of DS children begins to lag behind their cognitive development. Lexical knowledge (vocubulaly) is relatively unaffected (Fowler 1991). In fact, level of vocabulary development is lower than would have been expected based on level of cognitive development (Cardoso-Martins, Mervis and Mervis 1985). The social aspects of language or pragmatics in DS children are also relatively spared; conversational relevance, topic maintenance, and turn-taking skills are comparable to MA-matched controls. The causes for this disjointed development remain to be discovered (Beeghly, Weiss-Perry, and Cicchetti 1991). The results of a study on behavioral characteristics of DS subjects demonstrate that those individuals are more impaired with regard to sensory acuity and perceptual speed than are non-DS subjects of comparable age and intelligence levels (Clausen 1968). A review of the literature on the linguistic problems and language training of children with DS demonstrates that it is possible to obtain positive results in the linguistic development of these children if they are trained using specific pro-

grammes that take the interactive mother-child communication system into account (Monteiro and Prorok 1985).

Investigators have also reported that the occurrence of stuttering and cluttering appears to be uncorrelated with the case of DS (Breus 1972). A study examining the development of perception and cognitive abilities among nonhandicapped children and children with DS has shown that there is a similarity of the pattern of visual perceptual development of the nonhandicapped and DS subjects, matched for mental age, over the mental age range 2-7 years (Metcalfe and Stratford 1986). An application of a communication programme for DS children reveals that difficulties in all areas of language are confounded by sensory and perceptual deficits and that communication programmes addressing to the symptom complex of DS have to maintain elasticity (Glovsky 1972). An examination of the possible changes in flexibility with growth and maturation in DS children indicates that flexibility declines consistently with age in DS subjects and in normal age-matched controls (Parker and James 1985). The results of a study examining the effectiveness of the post-maturation treatment in changing the IQ of mongoloid children reveals that the children on post-maturation treatment show a decline in IQ with increasing age, as do untreated mongoloid children. This decline is no less marked among the treated children than with the untreated children (White 1969). In an assessment of the effects of intensity of training on sensory-motor development in infants with Down's syndrome, small short-term effects in favour of the matched intensive training (ITG) during the training have observed, but no long-term effects on development are evident following training (Sloper, Glenn, and Cunningham 1986). The use of drugs to modify behavior and to affect cognitive process of DS persons demonstrates no remarkable improvement in the status of DS individuals (Share 1976). The findings of a study on personality traits in institutionalized mongoloids strongly suggest that mongoloids do exhibit a constellation of personality traits, a constellation which can be recognized quickly and reliably even by untrained and naive observers (Domino 1964-65). However, it is to be noted that all individuals diagnosed as having DS do not have all the clinical features associated with DS. They usually have most of them. In addition, almost all DS individuals with a majority of those characteristics have varying degrees of mental retardation, with most in the moderate range of retardation.

Comparative studies on the growth and development of institutionalized and home-reared mongoloids during infancy and early childhood have shown that the home-reared group is significantly superior in mental test score and social quotient, although differences on the social maturity scale are limited in number (Stedman and Eichorn 1964-65). Also the factor structure of the social deprivation scale for mongoloid retardates hospitalized or awaiting hospitalization is generally similar to that for familial hospitalized retardates (Silverstein and Owens 1968). An evaluation of verbal operant conditioning with young institutionalized DS children demonstrates significant positive changes for group of DS subjects, receiving such as conditioning in an experimental setting, on the Stanford - Binet and 1 language measure (MacCubrey 1971). The findings of a study on forecasting mental growth for at -home mongols indicate that the prediction for a community-based mongol is about as reliable as for an institutionalized mongol. (Fields and Gibson 1971). A preliminary study of self-help skills and age in hospitalized DS patients reveals that mental age of the child determines the level of self-help skills which are, in turn, not significantly related to years of training represented by their chronological age (Ross 1971). In a survey on rate and age distribution of mongolism among inmates of Swedish institutions for mentally deficient Forssman (1960) notes that 9.8 percent of all the people enrolled in Swedish institutions for the mentally deficient were affected by mongolism. He interprets this figure by arguing that the rate of mongolism among the institutionalized is largely determined by social conditions. He particularly says that «a district with good room in its institutions will have more institutionalized mentally deficient, including mongolism, than one which has poor facilities for this purpose. Persons with mongolism are perhaps easier to keep at home than other severely feebleminded persons because they have such good dispositions and are so easy to manage, and so it may be that they are the last to be admitted if the institutions are overcrowded» (p. 33). Referring to the age and sex distribution of 1267 persons (percentage 9.8%) with mongolism at 203 Swedish institutions, Forssman (1960) notes that 63% of his series were children and 37% adults. Concerning the sex distribution of this mongoloid population expressed in percentage, the males accouted for 53.7%. Forssman (1960) also notes that several other authors have similarly observed a slight preponderance of males but they disagree about the reasons for it. The problem of integrating DS chil-

dren with severe learning difficulties is discussed by Budgell (1985). He discusses whether those individuals receiving mainstream education should be regarded as having severe learning difficulties (SLDs) and why there is a tendency for younger children with DS to be integrated into mainstream primary schools while older children still attend schools with SLDs. On this issue, Budgell (1985) particularly argues that «a general committment to young children that characterizes a romantic / humanistic ideology is at the heart of most admissions decisions for Down's syndrome children into primary schools». Data of a study examining demographic factors and the incidence of Down's syndrome in Ireland indicated that a uniquely high prevalence of DS exists in that country and that this is attributed to such factors as to comparatively high birth incidence. This is likely to persist given the nonavailability of amniocentesis and abortion and the presence of certain demographic characteristics, in particular a continuing relatively large family size (Mulcahy and Reynolds 1985). It is to be noted that DS affects 1 in every 600 to 700 infants and 1 in 2000 of the total population of the USA (Owens, Dawson and Losin 1971).

Investigators who examined some factors affecting age of walking in a mentally retarded population including children with DS have found that there is a relationship between age of walking and intelligence: all patients with IQ over 50 walked before 4 year; all who learned to walk after 7 year were profoundly retarded. Children with DS who remained at home tended to walk earlier than those in an institution (Donoghue 1970). The results of another study on DS and toddler temperament have shown that DS subjects are generally similar to the nonhandicapped individuals in terms of temperament characteristics, providing support for examining the temperament of DS children as a function of chronological rather than developmental age (Huntington and Simeonsson 1987). With regard to family background in mongolism, research found generally that the DS child do not seriously disrupt family life, at least in the early years (Carr 1975). Contacts with friends, relatives, and casual acquaintances continued as before. Also, a good deal of consistency was found in parental life. Crnic's (1991) review of the literature arrived at a similar conclusion. In spite of added stress, most families were coping adequately. Sloper et al. (1991) studied factors related to stress and satisfaction with life in families of children with DS.

Specifically, investigators found that 1) mothers of DS children do not report more problems than mothers of outpatient clinic children (Holroyd and McArthur 1976). 2) Mother's eye-contact frequency, facial expressions, and attempts at verbal communication meet with passive reception on the DS infants' part (up to 1-year of age), revealing a hypoactivity unfavorable to effective reciprocal (mother-child) interaction. This behavioral pattern persists up to preschool age with interactions still dominated by the mother, thereby maintaining the passivity of the child's reactions (Sarimski 1983). 3) Most changes in the characteristics of families with DS children are seen as the result of the introduction of the amniocentesis test, which is offered to older pregnant women (Shepperdson 1985). 4) Stress levels of mothers caring for a DS child are significantly higher than those reported by mothers of nonhandicapped children. Stress levels are higher among mothers whose children are a management problem, are abnormally active or underactive, are unable to occupy themselves for an hour or less, or are unable to play with others. Stress levels ara also higher among mothers who report that their social life and their time with their other children are severely restricted and that their health is being affected. Factors associated with higher stress also include having to move and having to spend more money on home heating equipment and supplies because of the DS child (Chetwynd 1985). 5) The quantity, complexity, content and attributional focus of mothers' internal state language is significantly affected by factors associated with DS children's developmental abilities, other DS child characteristics, differences in social context and mothers' opinions about their DS children's development (Beeghly, Bretherton and Mervis 1986). 6) Some parents of DS children and physicians think that those children's facial features negatively affect their social development while others think that facial plastic surgery might improve DS children's socialization (Pueschel, Monteiro and Erickson 1986). When an infant is born with DS, infant responses are reported to be delayed. Also infant characteristics that contribute to social interaction with caregivers differ between nonhandicapped infants and those with DS. Further, although DS infants, like nonhandicapped infants, develop social communication behaviors, vulnerable characteristics are found (Richard 1986). 7) There is no evidence that fathers, mothers, or sisters of mongols show consistently mongoloid deviations of 22 physical characteristics implicated in the microsymptomatology of mon-

golism (Buck, Valentine and Hamilton 1969). 8) Data of a longitudinal study of DS children (six weeks to twenty-one years old) and their families shows that, although adverse effects are fewer than might have been expected many parents, especially mothers, carry significant burdens. The highest level of problems are reported at 11-year of age. Mothers tend to find DS young adults easier to manage (Carr 1988). 9) Parents of handicapped children including mongols represent a heterogeneous population and as such have different needs for information and different perspectives of what is important and useful to them. Much depends upon such factors as the nature of their children's disabilities, their age, and their developmental needs. The parents' own level of adjustment to the child's disability shapes their demands for assistance (McLoughlin, Edge, Petrosko, Strenecky and Bryant 1985).

As far as integration of DS children in the primary school is concerned, it is to be noted that a longitudinal study of their cognitive development and academic attainments shows that the mainstream DS children make significantly greater progress in numeracy, comprehension and mental age and compare favourably on all other measures i.e. on expressive language, verbal fluency, drawing ability and reading (Casey, Hones, Kugler and Watkins 1988). In order to help these children improve their verbal communication skills, educators should 1) introduce language programmes as early in the DS child's life as possible; 2) enlist the active participation of parents, and 3) select intervention language targets that are based on the DS children's language development in general (Pruess, Vadacy and Fewell 1987).

In summary the bulk of the DS investigations presented above is concentrated on clinical and/or psychological traits of mongols reared at home or institutionalized and compared or not with non-mongoloid retardates. The main topics of the studies are related to issues such as personality characteristics and physical appearance, behavioral competence, life history and family quality of DS children and youth as well.

The Greek bibliography concerning research and / or review articles on mongolism in comparison to the international one is very limited. Most of the Greek DS studies come mainly from the medical science, particularly from neurology and psychiatry. The main topics investigated are referred to issues such as neurological, biochemical and clinical aspects of DS, parental reactions to the announ-

cement of the DS diagnosis, social help as well as protection for mental retardates including mongols. Greek physician investigators and/or foreign ones the articles of which have been translated into Greek examine in the last three decades of this century several aspects of DS such as neurological considerations of the atypical features of DS (Iakovidis 1963), DS with hyperthyroidism (Koutras, Proukakis and Politis 1965), the mentally retarded child (Doxiades, Iakovidis, Ierodiakonou, Sakellaropoulos, Tsagaraki-Missiou, Chrysostomidou 1965), syndrome of trisomy 18 (Chrysostomidou, Sinanioti and Valaes 1965), hyperthyroidism and seminoma in association with DS (Matsaniotis, Karpouzas and Economou-Mavrou 1967), mongolism from the editorial point of view (School Hygiene 1967), heredity and DS (Metaxotou-Stavridaki, Tsegi, Economou-Mavrou, Matsaniotis 1968), parental reactions to the announcement of the DS diagnosis in child (Valaes and Agathonos-Marouli 1969), the mongoloid child and his social environment (Perdicologos 1973), coexistence of DS with athyreotic hypothyroidism (Koutras, Kehayoglou, Papadoyannakis, Hartzoulakis 1976), monosomy syndromes (Kote and Katsantoni 1978), the high risk child (Karageli, Danezis, Diamantopoulos, Maganiotou, Maratou, Papadakou - Lagogyanni 1978), the human chromosome map (Kote 1978), spontaneous abortions caused by chromosomal aberrations (Moraitou-Lyberatou 1979), prevention of congenital and perinatal anomalies (Pantelakis, Varakis, Mousourou, Xanthou, Economou, Siganos 1981), the right to be different (Doxiades 1981) and Greek families of DS children (Marouli and Valaes 1978). It is to be noted that the last research is the most interesting and the most extensive in this area. Eighty-eight mothers of 89 DS children were interviewed in their homes using a questionnaire. At the time of the interview the children were 4-14 (mean 7, 5) years of age. Results of the research indicate that only 15% of the mothers found the care of the DS child creating a severe problem regarding their own household duties. Some families had no social life while others reacted to the peculiar situation with unusually frequent exits. Of the mothers 35% were severely depressed as a result of their child's deficiency. In only 20% of the families with other normal children the DS child markedly interferred with the daily life of his or her family siblings. In 45% of the families the father was very helpful in the care of the DS child while 25% of them were equally helpful with the care of their normal children. There was also a significant inverse relationship between the degree of the

handicap of DS child and the total functional scoring of the family. The follow-up interview five years later showed that 80% of the DS children demonstrated an improvement in their behavior and capabilities.

Few studies have, also, been conducted regarding personality traits of DS Greek children. Specifically, Paraskevopoulos (1971) in his research on attitudes of Greeks toward individuals with physical, mental and social handicaps found that individuals who are able to work and can serve themselves (f.e mentally retarded) are more preferred than those not having this possibility. Stasinos (1994) in his study on aspects of sexuality in Greek DS adolescents found that 1) those persons, like other adolescents, have the potential to express certain aspects of sexual behaviour provided that they live under adequate conditions in the community. 2) Adult Greek persons who have obtained a basic knowledge and/or experience regarding the DS adolescent may adopt positive attitudes toward him or her. Finally, apart from the limited researches appearing in the Greek bibliography on DS children, a brief review of (or reference to) the history and the clinical characteristics of the DS child appears in some theoretical considerations in paediatrics and psychology in Greece such as in the relative books of Matsaniotis (1972) and Paraskevopoulos (1977).

A review of the topics of Greek studies dealing with DS children reveals that the bulk of them is particularly referred to its biochemical and clinical characteristics. As far as we know, a few of them constitute case studies examining the DS child himself and his family environment as well. Such studies with DS children coming from districts as, for example, those falling in the North - Western (NW) part of Greece, particularly from the Epirus area are absent from the Greek bibliography.

As we mentioned above, the present study consists of five case reports concerning equal numbers of home reared DS subjects living in the towns of Ioannina (N=4) and of Egoumenitsa (N=1).

According to Shaughnessy and Zechmeister (1994), a case study is an intensive description and analysis of a single individual and the data for such a study may be obtained from several different sources including naturalistic observation, interviews and psychological tests, and even archival records. Bolgar (1965) has estated that the «power» of the case study method «lies in its ability to open

the way for discoveries» (p. 30). It acts as a natural starting point for forming hypotheses that may subsequently be pursued with more rigorous methodologies. In regard to the problem of generalizing from a single individual, Bolgar (1965) has stated that «much of the criticism leveled against the case study method of research is based on the accepted canon that it is impossible to generalize from one case»- (p. 30). Kazdin (1980b) notes, however, that the ability to generalize from one single case depends on the degree of variability in the population from which the case was drawn. Thus, when significant variability exists among individuals, as would be the case of measuring the constructs of learning and memory, emotionality, or personality, it becomes, in fact, impossible to claim that what is observed in one individual will hold for all individuals.

In light of this criticism, we adopted however this research method for the purposes of our study not to generalize from the cases selected since other DS individuals might differ from the subjects examined in any numerous ways, including intelligence, age, family background etc. The data of this research may act as a breeding ground for formulating hypotheses that may subsequently be pursued with more sophisticated methodologies.

The five cases examined represented the total number of DS pupils who attended special (and / or normal) schools or special classes functioning in those towns in the school year 1988-1989. They diagnosed as suffering from the Down's syndrome at the time of their birth at either state or private maternity clinics and they were described and recorded in special files by social workers appointed by the Ministry of National Education to have the social responsibility of the total number of special schools in Epirus.

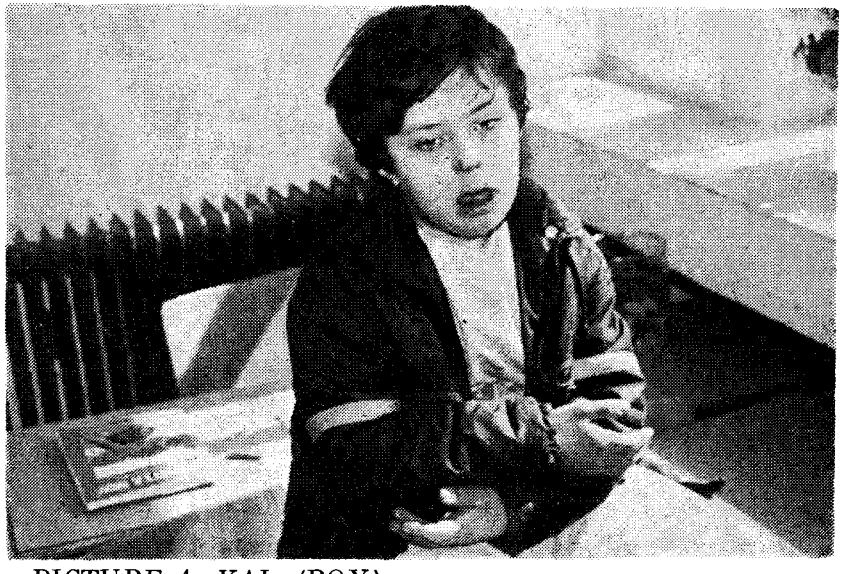
Parents of the DS children (in one case the mother only) were interviewed by the author at their homes using a limited number of generally open questions referred to the situation of the child himself (rate of growth and development, school achievement, interpersonal relations etc.), his (or her) family background (pregnancy of mother and child's birth conditions, parental reactions to the announcement of their child DS diagnosis, parent expectations for their DS child, effects of the presence of the DS child in family, attitudes of family siblings toward the DS child etc.) and attitudes of the public toward him (or her) as well. Children (3 boys and 2 girls) themselves were also observed by the author both in school settings and in their homes. Supplementary information concerning the school adjustment and the

school achievement of these children was obtained by interviewing their primary school teachers using some points of reference related to these issues. At the time of the interview the children's mean chronological age was 9,4 years, approximately. Their mean IQ score, according to the records kept by the school psychologist being responsible for the psychological guidance and evaluation of handicapped chilren in special (and/or normal) schools functioning in Epirus, was of about 55. Greek school psychologists in order to measure the child's intelligence usually use a revised version of the Wechsler Intelligence Scale for Children called the WISC-R which is however not standardized in the Greek reality. Also, they used to administer for the same purpose the Raven test. For this reason, we have to be somehow suspicious about the accurary of these children's IQ evaluation. Table 3 below presents some demographic and psychological data referred to those five DS cases we report in this study.

II. FIVE CASE STUDIES

Ist case.

KAL (see picture 1 below) a 9-year- old boy, is the 4th child of unskilled parents who live in a small village called Neokaessareia which is close to the town of Ioannina. He was born in a private maternity



PICTURE 1. KAL (BOY)

TABLE 3

Some demographic and psychological measures of the five DS cases reported, age of mothers in the time of pregnancy and the parents' occupation

DS cases	Child's demographic data					School	Mother's age in delivery time	Parent occupation	
	Sex	CA Y M	Birth order	IQ	siblings' number			Mother	Farher
1. DEP (KAL)	boy	8 11 7-2-79	4th	60	4	2nd spec. school Ioannina	33 (1946)	Housekeeper	Unskilled worker
2. LOL (IRE)	girl	9 2 28-8-79	2nd	65	2	12th Nor. school Ioannina	41 (1938)	Housekeeper	Pensioner
3. SKA (CHR)	boy	9 11 17-11-78	2nd	60	2	1st spec. school Ioannina	22 (1956)	Housekeeper	Technician
4. ZAV (GEO)	boy	10 8 15-2-78	1st	35	2	spec. school Ioannina	33 (1945)	Primary teacher	Primary teacher
5. LIO (HAR)	girl	8 4 3-6-80	3rd	55	3	spec. school Egoumenitsa	29 (1951)	Housekeeper	Craftsman
		Mean: 9,4years		Mean: 55					

Code: Y=Years, M=Months, Nor.=Normal, Spec. = Special.

clinic of this town on February 17, 1979. His mother, a housekeeper, was 33 years old at the time of delivery. Before that, she was admitted to the Alexandra Maternity Clinic in Athens, in 1973, a few days after the death of her 9-year-old 2nd child. She had there an 1-month uterus treatment. During pregnancy of her 3rd child she also had a thyroid treatment following an abortion. Mother continued to have such a treatment during the first four months of the pregnancy in KAL that, according to her personal estimation, was almost normal. The wheight of the newborn was 4 3/10 kgrs. Mother described the newborn's body as being very «slack» and «alike a paste». Soon after his birth, clinical features of mongolisms had been noted by the family paediatrician. Mother was informed by him that her child «had a problem» as suffering from the Down's syndrome and a heart disease as well. She then felt very badly as she explained to us. Moreover, nurses of the clinic tried to advise her as well as the baby's father *to leave him to die* because they thought that this was the best solution to their problem. However, although the baby's case was indeed very serious, parents decided not to follow such an advice.

At the age of 9 months, baby was suffering from a high fever and a spasm. Then he was admitted to the local «Hatzicosta» General Hospital and stayed there for $3^1/_2$ months approximately in order for him to have a treatment for these symptoms. During the treatment period, parents of the child were advised again *to leave him to die.* Particularly, the director of the Paediatrics Clinic told child's mother that «he will tire them». Mother however did not agree with that paediatrician's painful opinion. Since local hospital physicians were unable to make a clear diagnosis of the boy's illness, he was admitted to the Children's Hospital in Athens where he had an 1-month treatment without however presenting any improvement in his health situation. A hospital doctor soon after the boy's return from Athens informed his mother that the child's illness was probably related to staphylococcus. The child was then admitted again him to the «Hatzicosta» General Hospital of Ioannina in order for him to receive a staphylococcus treatment. However, he continued to suffer from a high fever. Since the child's health situation continued to be worse, his parents being anxious about its consequence decided to visit Sweden where the child was admitted to a Children's Hospital in Stockholm. He stayed there for about 4 days. Swedish paediatricians made exactly the same diagnosis of the child's problem i.e. as suffering hoth from the DS and a heart disease.

KAL's walking age was of about the 4th year while his articulation age was the 8th year. At this time he started to speak badly the following easily articulated words: «mama» (mother), and «papa» (father). Nowadays, KAL, a 9-year- old boy, is able to articulate also badly a few words only such as «ela» (come on), «pame» (let's go), «ela re» (come on stupid), «ase re» (leave it stupid), «mpala» (ball) etc. However, taking into acount his overall articulation competence one may characterize him as suffering from the symptom of alalia. His usual communication scheme with others in and out of school environment was (and is still being) mainly based on the use of gestures and /or *whistling* (use of a non - verbal communication).

KAL first attended a normal infant school in his village for three years and then a special school (or a special class) in Ioannina for another 3 years. According the child's teacher, although he was unable to speak, he could communicate with others and fulfil their orders. Also he sought to be praised for his endeavours irrespectively of their outcome. KAL usually tried to imitate the classmates' behavior. When behavior of others embarrassed him, he used to defend himself very actively. Some of the older pupils tried to protect him while others disturbed him. Teacher estimated that KAL's communication skills had been improved presumably because of his special class involvement and his everyday relations with other pupils from normal schools as well. It is to be noted that a number of ordinary schools share the same building with the special class that KAL attended.

According to KAL's mother, his situation offends his family siblings rather than his parents. Also parents are very anxious about the DS child's rehabilitation in the future. Since they recognized that there is no state care for the possible occupational training of such individuals, they decided to marry their 2nd child-daughter who lives with her husband together with KAL in order for him not to be alone in the future. His mother told us that the state should try to do something for those individuals in order for them to avoid to be (as KAL's mother said) «masterless dogs» within the Greek society. Sometime, KAL's mother, according to his school teacher, expressed to him (i.e. the teacher) her wish to shut the child up in a asylum presumably in order for her to ensure his exclusion from the engagement and marriage ceremony of her daughter. Since teacher did not agree with such a wish of KAL's mother, she accepted to continue to live together with him.

their child's problem and they decided to care for her in the same way as in the case of their first child.

IRE's walking age was the 3rd year while her articulation age was the 5th year. However, at that time she was unable to complete the articulation of one word. Also, she had (and still she has) a stuttering problem particularly with the pronunciation of the Greek letter «γ». She attended first an ordinary infant school for one year and then an ordinary primary school for three years at the moment. According to her teacher, IRE can read and write almost easily, she has a very strong memory and a conception ability related to spelling of Greek words already learned by her. Also, IRE likes music and dancing. A 14-year- old female sibling being in excellent health did not (and does not) know anything about the IRE's problem. Parents decided themselves not to inform their normal daughter about IRE's Down's syndrome. Also they were not interested in seeking to know about the possible reasons behind the IRE's problem. They had not visited any doctor in order to ask him about the Down's syndrome of her daughter because (as they explained to us) they initially accepted her situation as it was and they were convinced that there is no possibility for her complete therapy.

Parents had not faced any problem with possible negative attitudes of others in the Ioannina community toward IRE. According to them, this happened because the DS child could well communicate verbally with others while her Down's syndrome physical stigmata are not so clear to others. However, they admitted that they were suffering from inferior feelings because of the IRE's problem.

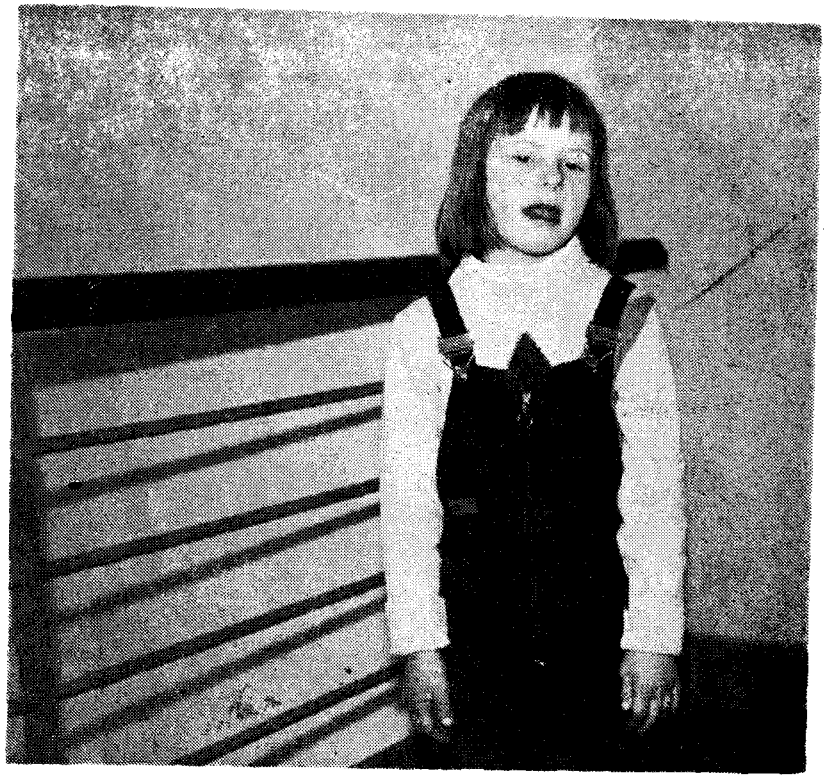
3rd case

CHR (see picture 3 below), an almost 10-years-old boy, is the second child of parents living in the town of Ioannina and having alltogether 2 children. He was born in a private maternity clinic of this town on November 17, 1978. His mother, a housekeeper, had an abortion before her pregnancy in CHR. The pregnancy was almost normal. During that period she had a blood pressure 8 approximately. Mother realized her embryo more early that in the case of her first child. According to her, the embryo was very active and she was joking about it by saying often that it will become «a good footballer».

At the time of delivery, baby shallowed a great amount of blood as mother explained to us. She was 22 years of age at the time

2nd case

IRE (see picture 2 below), a 9-year-old girl, is the 2nd child of parents having altogether 2 children and living in the town of Ioannina. She was born in a private maternity clinic of Ioannina on August 28, 1979.



PICTURE 2. IRE (GIRL)

Her mother, a housekeeper, delivered her first child after a delay of 12 years since her marriage time. During that period, she had an uterus treatment and a preventive abrasion as well. Her pregnancy in IRE was normal. She was 41 years old at the time of delivery. According to her, the embryo appeared to be less active in her womb than her first child was.

Parents were informed by their paediatrician that their child was suffering from the Down's syndrome. However, they accepted

their child's problem and they decided to care for her in the same way as in the case of their first child.

IRE's walking age was the 3rd year while her articulation age was the 5th year. However, at that time she was unable to complete the articulation of one word. Also, she had (and still she has) a stuttering problem particularly with the pronunciation of the Greek letter «γ». She attended first an ordinary infant school for one year and then an ordinary primary school for three years at the moment. According to her teacher, IRE can read and write almost easily, she has a very strong memory and a conception ability related to spelling of Greek words already learned by her. Also, IRE likes music and dancing. A 14-year- old female sibling being in excellent health did not (and does not) know anything about the IRE's problem. Parents decided themselves not to inform their normal daughter about IRE's Down's syndrome. Also they were not interested in seeking to know about the possible reasons behind the IRE's problem. They had not visited any doctor in order to ask him about the Down's syndrome of her daughter because (as they explained to us) they initially accepted her situation as it was and they were convinced that there is no possibility for her complete therapy.

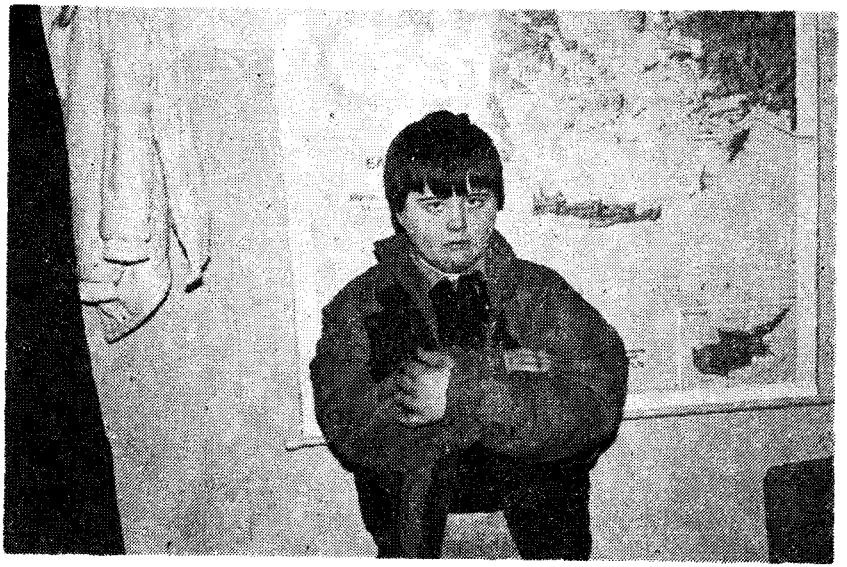
Parents had not faced any problem with possible negative attitudes of others in the Ioannina community toward IRE. According to them, this happened because the DS child could well communicate verbally with others while her Down's syndrome physical stigmata are not so clear to others. However, they admitted that they were suffering from inferior feelings because of the IRE's problem.

3rd case

CHR (see picture 3 below), an almost 10-years-old boy, is the second child of parents living in the town of Ioannina and having alltogether 2 children. He was born in a private maternity clinic of this town on November 17, 1978. His mother, a housekeeper, had an abortion before her pregnancy in CHR. The pregnancy was almost normal. During that period she had a blood pressure 8 approximately. Mother realized her embryo more early that in the case of her first child. According to her, the embryo was very active and she was joking about it by saying often that it will become «a good footballer».

At the time of delivery, baby shallowed a great amount of blood as mother explained to us. She was 22 years of age at the time

of delivery. Parents were informed about the Down's syndrome of their child soon after his birth. According to their descriptions, they had mixed feelings in that time such as anxiety, distress and disappointment. However, they realized soon the seriousness of their child's problem and its bad consequences for his life in the future.



PICTURE 3. CHR (BOY)

CHR's walking age was the 3rd year approximately while his articulation age was the 1 1/2 year. However, his walk and speech initial time was very late in comparison to that of his family sibling. Also he was unable to walk easily for a long time. Often, he was feeling tired soon after an extensive walk. According to his mother's description, he cannot articulate correctly even one word. He pronounces, for example, the Greek word electrologos as «metologos» presumably because it is more easy for him to articulate it just in that form as not including consonant junctions. When he cannot articulate correctly a word he is usually embarrassed.

CHR first attended a normal infant school in Ioannina for only three months because, as his mother explained to us, his teacher used to seat him at a corner desk behind of the classroom and her attitude towards him was bad. During the CHR's preschool age, his parents visited a paediatrician in Athens who told them that there will be an improvememt of the DS child's situation. She advised them

to buy from France some expensive pills in order to increase the child's mental development. The child had taken such pills for a certain period of time in his preschool life. CHR when was 4 years of age received a private speech therapy for at least six months. It is to be noted that the speech therapist promised parents that their child will have a promising improvement in his speech ability within six months from the onset of his speech treatment. However, according to his mother's opinion, her child's speech had not improved at all afterwards.

CHR attended a special school in the town of Ioannina that shares the same building with schools for normal children. According to his teacher's estimation, other teachers from normal schools used to stigmatize both the DS child himself and his parents. He has a very strong memory and a good observation ability as well. His teacher explained to me that, if CHR has at his disposal visual experiences, he can understand the meaning of a text while he cannot discriminate colours. Because of his excessively grown body (comparing with his age), classmates coming particularly from normal schools used to banter him by saying «strangler», «abnormal», «stupid» etc. However, teacher estimated that the attitudes of other pupils toward him were in some cases positive and in some others negative.

His parents estimated that the public attitude toward their DS child was generally positive. However, they were very anxious about his future life because of lack of a state policy concerning the rehabitation and welfare ot handicapped people in Greece, in general.

4th case

GEO (see picture 4 below), an almost 11-year-old boy, is the first child of parents who work both as primary school teachers and live in the town of Ioannina. He was born in a private maternity clinic of this town on February 15, 1978. The wheight of the newborn was 3.500 kgrs. Mother had an almost normal pregnancy. During that time she was however embarrassed for reasons associated with her marriage. Apart from that, she wanted strongly to have her first child. She was 33 years of age at the time of delivery.

Parents were informed by a paediatrician that their child was suffering from the Down's syndrome soon after the delivery. Father was informed first about his child's problem. As mother explained to us, he was very surprised about it and since he could not believe

it he was so embarrassed for such an announcement that he wanted to leave the baby *to die.* Particularly he contended that because of the presence of such a child in his family his pride will probably be

PICTURE 4. GEO (BOY)

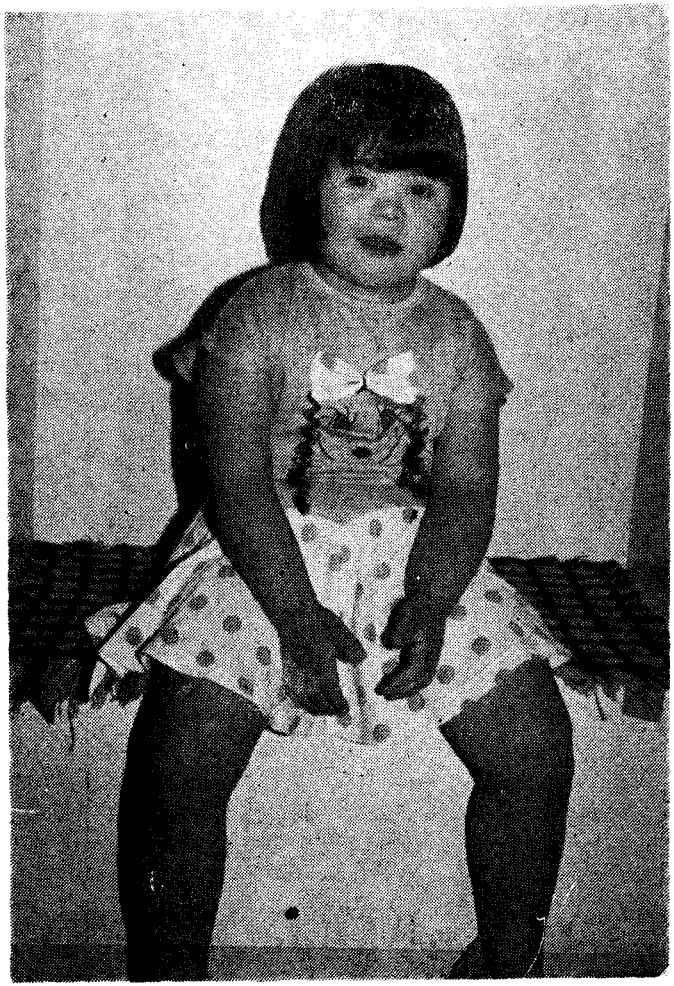
grazed. He was saying characteristically «I don't have a child». Later, he did not want to taking out the child for a walk. According to his wife personal estimation, he probably faced some psychological problems resulted presumably from their child's problem. Mother, on thecontrary, accepted her child with his DS problem because, as the explained to us, she believed that he would be improved in the future. The parent relations started thus to be disturbed by blaming each other for the presence of the child's Down's syndrome.

GEO's walking age was about the 6th year while he started to articulate the first word in his lst year. However, he could articulate a few words such as «mama» (mother), «mpampa» (father), «pame» (let's go), «meta» (after) etc. GEO had received a worktherapy in his preschool age while he cannot hear from his right ear. He attended an ordinary infant school in his village for one year and a special school in the town of Ioannina for 5 years at the moment. However, he cannot read and write thus developing a non

verbal communication. He cannot also grasp appropriately a pencil to write and/or a spoon or fork to eat by himself. Further, he likes to be praised while he learned to raise his hands when he feels happy. He likes also to keep always clear and in order his school books and booknotes.

5th case

HAR, (see picture 5 below) an 8-year- old girl, is the 3rd child of parents living in the town of Egoumenitsa. She was born in the



PICTURE 5. HAR (GIRL)

General Hospital of Ioannina on June 3, 1980. The wheight of the newborn was 3.600 kgrs.

Mother, a housekeeper, had a normal pregnancy. She was 29 years of age at the time of delivery. Father was informed first by a gynaecologist that his child is probably suffering from the Down's syndrome. He felt badly with that announcement. Mother, as she explained to us, when was told about it felt inside a «gap» and a «disappointment» because she did not believe that. In fact, parents did not know anything about the nature of the syndrome before the baby's birth. They then visited the Health Hospital in Athens hoping that the child's DS diagnosis was probably not correct. However they took almost the same answer concerning their child's mental situation. The only difference in the diagnosis procedure was that the child was suffering from a peculiar chromosome pattern called «mosaic».

HAR's walking age was the 2nd year and she started to articulate the first words also in that year of her age. However, she faced some stuttering problems. She attended first a normal infant school and then she was admitted to the special class of the lst school for normal pupils in Egoumenitsa. According to her mother, HAR was unable to concentrate herself easily on a stimulus. However, the attitude of the public and her normal classmates toward her was almost positive. Mother wanted for her to try to approach the normal child's behavior and to become her able to live in the Greek community without any problem as well.

III. DISCUSSION

The majority of the data, both quantitative and qualitative, concerning the DS cases reported above appear to be, to some extent, in accord with theoretical issues regarding the DS in children and almost similar to findings of previous retative studies conducted in abroad and in Greece as well.

Specifically, in the group of five cases involved there was a slight preponderance of male (an analogy of 3: 5). Their IQ scoring was for most of them at the mild level while the only child with the mosaic chromosome pattern had achieved the highest IQ score. It should be noted that this form of DS (i.e. the mongoloid condition of mosaicism) is the most variable in terms of appearance and level of intelligence functioning (Jarvick et al., 1964; Gibson and Pozsonyi 1965). Something similar to present fin-

dings has also been reported by Shipe et al. (1967-68). Kirk (1972) noted however that the child born with the DS at a later age can range in IQ between 20 and 60, with the large majority in the 30 to 50 IQ range. Thus, as Hallahan and Kauffman (1978) stated, the degree of retardation ranges widely with most DS individuals falling in the moderately retarded range.

In regard to walking and the language acquision (articulation) age, cases examined demonstrated an almost long delay in both developmental stages. Particularly, in some cases (as, for example, the cases 4th and 5th for the walking age and the cases 2nd and 4th for the articulation age) there was a big gap between the related measures. In both delays of their development the bigest one appears in DS girls. The important thing on this issue is the very common characteristic of all cases that was their inability to communicate *verbally* with others. This evidence is in accord with Johnson and Abelson's (1969) statement that the Down's syndrome usually raises a child's problem to communication with his (or her) surrounding. Hallas, Fraser, and MacGillivray (1982) stated that perhaps the most crippling problem for the mentally handicapped is communication, either vocal or non-vocal (gestural) and that they suffer, also, from a large variety of speech disorders. There is a common finding between researchers indicating that DS children experience delay in the acquisition of language which is related to their intellectual, social, and motor development (Pruess, Valacy, and Fewell 1987).

Mother's age at the time of delivery also varied. Thus in one case (i.e. the 3rd case) her age in that time was 22 years while in another one (i.e. the 2nd case) that was almost twice as high. It should be noted that the likelihood of having a child with DS is dependent to a great extent on the mother's age with more such children born to women under 20 and over 40 years (Hallahan and Kauffman, 1978).

Parental reactions to the announcement of the DS diagnosis in a child were not the same in both mother and father. However, both initially felt very badly while afterwards mother usually accepted her DS child and father continued to be very anxious and depressed because of this child situation unexpected. Noteable is also the fact that in some cases doctors following their diagnosis advised the parents of the DS child to solve the problem by *leaving him (or her)* to die. That was, in fact, an unlucky and totally unexpected advice of doctors that parents, presumably for various reasons, did not fol-

low. This event explains perhaps the possible rejecting feelings of the broad public in Greece about the mentally, handicapped individuals as a whole. Hallas, Fraser, and MacGillivray (1982) noted that when the doctor is certain of the DS diagnosis and the degree of handicap he (or she) should explain the truth to both parents, comprehensively. According to them, conflicts and misunderstandings arise if parents learn facts separately. They noted also that the doctor has to be able to respond to questions of prognosis of the DS child's situation which should not go unanswered.

In regard to parents' dilemmas and the effect of family life it should be noted that although «patterns of family life are not so-easily disrupted as one might expect by a young handicapped child» (Younghusband 1970), parents may be overwhelmed by the birth of such a child and information giving can modify attitudes and help to ease such disturbed feelings (Hallas, Fraser, and MacGillivray, 1982). McLoughlin et al. (1985) noted that parents of handicapped children including mongols represent in fact a *heterogeneous* population.

Finally, taking the findings of the present study as a whole one might argue that because of the kind of research method used they may be treated as a breeding ground perhaps for formulating hypotheses that may subsequently be pursued with more rigorous research methodologies in a more broad sample within the area of DS in Greek children about which relatively little is known.

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