HEALTH CARE AND HEALTH PROBLEMS OF CHILDREN IN SPECIAL EDUCATION

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Abstract

The objective of this study was to determine the health care needs and patterns of care obtained by children in special education. Parents of 751 children of high school age from lower socioeconomic areas of one Community Health Department in Montreal were surveyed. The children were divided into 3 groups according to their educational placement (mildly mentally retarded, educationally retarded, and "normal" controls). There was a lack of primary care in all 3 groups. Gaps in specialty services of many types were apparent in the retarded group. For both the retarded and educationally handicapped groups there was a lack of services in the dental and psychiatric areas. Coordination of services for the retarded appears to be poor in the Montreal area, and the Departments of Community Health should review their role in providing such care. School health services should form a part of the overall care of the retarded (as well as other handicapped children), specifically by reorienting to become more of a coordinating and linking service with facilities available in the community.

Résumé

Le but de cette thèse était de déterminer les besoins de santé et les moyens d'obtenir les soins pour les enfants en éducation spéciale. Les parents de 751 enfants des écoles secondaires des régions défavorisées d'un Département de Santé Communautaire à Montréal ont été étudiés. Les enfants étaient divisés en trois groupes en accord avec leur placement d'éducation (moyennement retardés mentaux, lents à l'école, et les controles normaux). Il y'avait une manque de soins primaires dans les trois groupes. Des manques de services spécialisés de toutes sortes existaient dans le groupe des retardés. Pour les retardés et les lents il y'avait une manque de service dans les domaines dentaires et psychiatriques. La coordination des services pour les retardés semble être faible dans la région de Montréal, et les Départements de Santé Communautaire devraient examiner leur rôle dans ce domaine. Les services de Santé Scolaire devraient faire parti des soins globaux des retardés (ainsi que les autres enfants handicapés) spécifiquement en se réorientant pour devenir un service plus coordinateur avec les facilités disponibles dans la communauté.

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SECTION I

INTRODUCTION

I. The Problem

Historically, School Health Programs in Quebec were a municipal or district health unit responsibility which was shared with the school boards. In 1970 the report of the Castonguay-Nepveu Commission[1] on health and social services, laid the groundwork for a transfer of this responsibility to a reorganized health service, completely out of the jurisdiction of the municipalities and the school boards. The law which was subsequently passed by the National Assembly (Chapter 48, 1970) regionalized health services. Quebec was divided into 13 regions each with supposedly autonomous regional councils. Within the territory of each regional council, primary health care services were to be delivered through local Community Service Centres (CLSC's) which would have community support and serve populations of roughly 30,000. Secondary level specialized care was to be provided at hospital centres (H. C.) in the region, and university associated H. C.'s in the three largest cities would provide tertiary care.

A mechanism for providing public health services was added just before the Bill was passed, and it created Departments of Community Health (Départments de Santé Communautaire, or DSC to use the French abbreviation), with responsibility for preventive, therapeutic, and rehabilitative services for a population of roughly 200,000. Each DSC is based in a parent H. C. and has a protected budget from the Ministry of Social Affairs (MAS). The director of the DSC enjoys the

status of a full department head in the parent hospital. The role of the DSC is to "analyze and evaluate health problems, evaluate the population's state of health, and coordinate community resources."[2] It must also identify target populations to whom health programs can be applied.

The role of DSC was primarily conceived of as an advisory and coordinating body without a lot of regulatory authority. It was assumed that most services would actually be delivered through the CLSC's. However, as things have evolved, the CLSC's presently deliver only about ten percent of the personal health services provided in Quebec, with the private sector and the Hospital Centres providing the rest. As a result, the DSC's have been forced to get into the service delivery business in certain areas where important preventive services had to be provided, such as Maternal and Child Health, School Health and Occupational Health, to name a few. An excellent review of the changes which took place in the Quebec Health System between 1967-1977 is provided by Lee.[2]

As things were conceived in Chapter 48, personnel from municipal and district health units were to be transferred to the DSC's or CLSC's wherever their respective talents were required. However, the actual transfer required many years to complete and it was only in the late 1970's that the transfer of municipally employed school health nurses in Montreal was completed, and School health programs became a DSC

problem.

In Montreal the school health program which had evolved was a highly traditional one. Both nurses and school physicians were employed. The evolution followed the pattern outlined by Clemmens[3] which occurred all over North America. Originally viewed as a means of control of infectious disease, it turned to routine physical examinations of children after World War I (a phase which was just ending at the time Chapter 48 became law) and finally becoming screening-oriented with greater public health nursing input in the 1960's. However there are many different school commissions on the Island of Montreal, and their boundaries do not necessarily coincide with those of municipalities. School commissions and individual principals all had their own ideas about the role of the school health personnel. Often they were viewed as a first aid service, and a protection against legal liability in case of injury or illness occurring at school. Thus in many areas, actual public health programs were often the secondary objective of school health services.

This then is the context in which the DSC of the Montreal General Hospital found itself in 1978. The DSC serves a segment of West-Central Montreal with a population of nearly 250,000 which includes both the poorest and the wealthiest sections of the city. The school commissions operating in the area include the Protestant School Board of Greater Montreal which is English, and the Commission des Ecoles Catholiques

de Montréal (CECM) which has both a French and an English division. Because this DSC is the only one which functions largely in English, it was also assigned the responsibility to provide school health services to several English special schools for the mentally retarded which are actually geographically outside the territory of the DSC.

The first step of the DSC was to hire a nurse coordinator to organize the program. Then negotiations had to take place with the school commissions to lay the groundrules for the service which was to be primarily public health programs and not first aid services. The transfer of nurses from the municipal service took place and nursing personnel were apportioned to schools on the basis of a ratio of approximately one nurse for 2000 pupils in regular class, 1000 special class and 500 special school pupils. No school physicians were retained in the program. The groundrules for provision of health services were that personal health services required by pupils, no matter how they were discovered, were to be provided by the family's own source of primary care. A nurse who discovered a child with a problem had to send a note to his parents asking him to seek consultation with his physician who was supposed to return the note complete with his findings to the school nurse.

It quickly became clear that there were some problems with this system at all levels, but particularly in the special schools and special classes. Nurses working in these areas felt that there were large

numbers of health problems, and that most of their requests for consultation went unfilled. Communication was only rarely received from the practicing physician.

Because of the large number of special students served by the DSC, a pediatrician was hired one day per week to work with the coordinator to examine the problems of the special education pupils. He started by visiting some of the schools (which served largely lower class populations). He concurred that there were indeed many health problems among these students and that many of them had no primary care at all. However, it became clear that some solid data was necessary if the program was to be rationalized. This project was undertaken therefore with the following objectives in mind:

1) To provide data on the expected needs for health services of retarded children and children in other types of special education through a review of the pertinent literature.

2) To obtain data on the known health problems of a sample of children in normal and special classes served by the DSC, and to compare these with the expected needs.

3) To discover the extent to which these students were linked with primary and specialist services, and how they utilized health services and

4) To make some recommendations for the school health services based on the findings.

SECTION II

LITERATURE REVIEW

II Review of the Literature on Medical Problems in Retarded and Educationally Backward Children

II. 1 Introduction

In searching the 'literature', it proved impossible to find a good factual review of the literature on the medical requirements either of mentally retarded children or children in special education. Only Conley[4] in his book on the Economics of Mental Retardation has approached the question for the retarded. He relies heavily on several American and British epidemiological studies in which for various reasons the ascertainment of cases is likely to be incomplete. The diagnosis of medical problems given in these studies relies on reporting of handicaps by medical services which exist in the community, and which in all likelihood are underutilized by the population of retarded persons. Clinical studies of retarded populations on the other hand, are more likely to come close to the true prevalence of handicapping conditions. They are, however, subject to the biases of sample selection and overdiagnosis by the physicians involved. It is the objective of this thesis review to combine the results of some of the better studies of each type, and to make a "best guess" estimate of the true prevalence of certain conditions among the retarded.

It is of course necessary to consider degree of retardation as a factor in the analysis, and this is divided into two categories; severe and mild. A further objective is to examine the literature on medical

problems in that large group of children who are in special education but whose intelligence levels do not fall into the retarded ranges. This literature proved to be almost non-existent and those studies which are available are often difficult to compare because the samples are poorly described. Nevertheless a section at the end of this review will describe what is known about these groups.

The literature review covered principally the past twenty-five years and was performed by hand. Rehabilitation Literature which abstracts all important articles related to the retarded, "brain impaired", minimal brain dysfunction,and special education, was used as a major source for references. All the available literature was reviewed, and papers mentioned in the bibliographies of these articles were screened and examined where deemed appropriate. Unfortunately, a few of the often quoted epidemiologic studies were published in book form and were difficult to obtain.

II. 2 Epidemiology of Mental Retardation

It is essential to have an overview of the problem of mental retardation from the community viewpoint. As is often the case with symptoms or symptom complexes, there are some problems with the definition to begin with. The World Health Organization expert committee[5] emphasizes that assessment of intelligence should take into account both social competence and intellectual ability , or scholastic aptitude. However the authors then acknowledge the difficulties involved in measuring social competence, and fall back on the International Classification of Diseases which defines mental retardation on the basis of standardized Intelligence Quotient (IQ) tests with any individual whose IQ is more than 2 standard deviations below the mean being retarded. In terms of most IQ tests this means an IQ of less than 70. Mental retardation is further broken down into 4 subdivisions as shown:

Table 1: Classification of Degree of Mental Retardation

	S.D. from mean	IQ range
mild	-2.0 to -3.3	50 - 70
moderate	-3.3 to -4.3	35 - 49
severe	-4.3 to -5.3	20 - 34
profound	-5.3	0 - 19

The report mentions the fact that IQ is not necessarily a fixed attribute and may change due to numerous factors including differential

rates of maturation, education, social environment and culture. They also point out that IQ tests may be standardized differently and therefore give variable IQ ranges for the retarded, and that the diagnosis of retardation will vary from society to society. The above definitions are also agreed upon by other agencies dealing with the retarded, such as the American Association of Mental Deficiency (AAMD).

In spite of this agreement, the reviewer found tremendous differences in the criteria used by investigators to classify mental retardation. In virtually all of the epidemiological studies, only 2 categories of retardation were used: severe (IQ < 50) and mild (IQ 50 - 70). However Birch[6] included up to IQ 75 in the mild category, while Drillien[7] accepted up to IQ 54 for her category of severe, and 55 to 75 for mild. Other authors have included IQ's up to 85 in their definition of mild retardation. Thus it is essential to look at trends across large numbers of studies to estimate the true prevalence of mental retardation.

Definitions of mental retardation based on IQ rest on the assumption that intelligence exists in the population in a more or less normal distribution, and the difference between "retarded" and "normal" intelligence is basically a statistical concept. Social competence is of course extremely important in determining how an individual will get along. In modern technological societies compulsory education frequently proves difficult for the retarded, resulting

in school failure. There is another large group of children who are not retarded in the statistical sense, but who fail to meet the cognitive demands of education and end up in special classes. This group is probably composed of a mixture of children with boderline IQ's (70-85), and others with so-called specific learning disabilities (SLD). There is reason to suspect that this group of children may have a higher prevalence of medical problems than the "normal" population.

Problems associated with severe mental retardation are the best documented. Abramowicz and Richardson[8] provide a very useful review of the 27 most important community studies of severe mental retardation (IQ < 50). The most reliable studies according to these authors, are the British and Scandinavian studies because of better ascertainment of cases. The prevalence is remarkably similar in all these studies with a combined figure approximating 4 per 1000. However Berenson[9] discovered, by means of door to door survey in the town of Aarhus, that even in Sweden only $^2/_3$ of the cases of severe mental retardation were known to authorities. Thus it is possible that the prevalence rate of 4 per 1000 is a slight underestimate.

It is interesting to note that there is no change in prevalence of severe mental retardation between 1926 and 1975. Virtually all of the studies examined show no social class bias for severe retardation. Etiological factors could be determined in roughly half the children with Down's syndrome making up from $^1/_6$ to $^1/_3$ of the severely retarded children. 50% were diagnosed as having multiple

handicaps primarily on the basis of medical history. They noted the tremendous variability between studies of the reporting of specific types of neurological and sensory handicaps.

The epidemiology of mild mental retardation is somewhat different. There is a wide range of variability in prevalence estimates from Drillien's[7] estimate of 6.9 per 1000 in Edinburgh amongst children aged 7.5 to 14.5 to Birch's[6] figure of 26.9 per 1000 in Aberdeen children aged 8 to 10. Both of these studies were combined epidemiologic and clinical studies. Methodologically, Birch[6] seems to have been the most thorough but one reason for his high figure is that he includes children with IQ's up to 75. Drillien tries to explain her figures on the grounds that Edinburgh is a relatively wealthy city with fewer children from lower class families. Virtually every study of children with mild mental retardation shows a very strong class bias in this category with higher prevalence in lower class families.

Most studies have found physical handicaps to be more prevalent among mildly retarded children than amongst normal children but less so than among the severely retarded. Specific handicaps are alluded to below.

It should be noted that the prevalence of mild mental retardation changes with age in most studies, reaching a peak in the late school years and then dropping off again in late adolescence. This is because the academic requirements of compulsory education unmask cases

of mild retardation in developed countries at least. The rates appear to drop off, not due to death or cure, but due to the fact that given reasonable social competence, a person with a boderline IQ can become indistinguishable from the rest of the population in early adult life.

II. 3 Mortality in the Retarded

From the few studies which are published specifically examining this question it would appear that there is a significantly elevated mortality rate among the retarded. However, the two studies with the most extensive data[11, 12] are based on institutionalized populations. While some epidemiological studies give data on entire community populations, they do not differentiate between those in institutions and those in homes. Nevertheless the institutional data of Forsmann and Akesson[11] from Scandinavia is based on 12903 subjects followed over 13 years. They found a mortality rate 3.2 times that of the normal population. The excess mortality varies by age and degree of retardation as follows:

Table 2: Excess Mortality Among the Retarded

	Excess Mortality	
Age	Mildly Retarded	Severely Retarded
0 - 10	7.4X	36.4X
10 - 15	3.1X	62.5X
15 - 20	3.4X	21.4X

Children with epilepsy had higher mortality rates at all ages. Richards and Sylvester[12] examined the excess mortality for institutionalized retarded persons in England and Wales by cause of death. Respiratory causes were the most common single cause of death and the highest rate of mortality occurred in the 10 - 19 year age group. In all studies

examining mortality among severely retarded people there is a higher mortality rate among females for unexplained reasons.

Thus, in spite of a dearth of data, there is evidence of higher mortality rates among even mildly retarded children in institutions. However, whether this is also true for mildly retarded children outside institutions is still a matter for conjecture. Implications of the higher mortality are firstly that it must be taken into account in prevalence studies of the retarded, because the prevalence and "case-mix" will change with age, and secondly, since much of the mortality is due to treatable conditions,it highlights the need for good medical services for this group.

II.4 Neurological Disorders

Most physicians dealing with the retarded would agree that neurological problems are common, and it stands to reason that there should be. However the real question is how common are they? There are four studies with reasonable methodology which report the proportion of children with neurological abnormalities. Beck[13] in a retrospective analysis of records of 252 mildly retarded children estimated that 60-65% would have a "neurological diagnosis" and then verified this by examining 45 children in one class at the same institution, finding such a diagnosis in 67%. However selection factors and diagnostic criteria are unclear. Drayer[14] in 1958 examined the records of 50 randomly selected mentally retarded patients diagnosed and followed in a pediatric-psychiatric clinic and found slightly more than half with neurological problems. This population presumably covers the entire range of retardation. Smith[15] performed neurological examinations on 304 institutionalized children and found 45% with a neurological problem. The three previously mentioned studies all suffer from some methodological and definition problems but the rates of neurological handicap are nevertheless fairly consistent.

The best study of neurological handicap is the epidemiologic study of Birch[6] in Aberdeen. In this report there was almost certainly a very high rate of ascertainment of cases in the community and

all the cases were examined by a neurologist. The only problem is that Birch included in his sample some children who should probably be classified as boderline retarded or normal. He found a rate of neurological problems of 51% in his entire population with a significant difference between severe (73% neurological problems) and mild (26% neurological problems). For this part of the study his cut-off point between severe and mild retardation was an IQ of 60 on the Weschler Intelligence Scale (WISC), which is an unusual dividing point.

The neurological problems of specific interest in terms of medical care of retarded children are convulsive disorders and cerebral palsy. Epilepsy is defined as a paroxysmal cerebral dysrhythmia which manifests itself by periodic convulsions or seizures. The clinical manifestations are visible only during seizures and thus it is difficult to examine specifically for epilepsy. Diagnosis relies on adequate historical documentation of attacks. Epidemiologic studies including those in which the children are examined, can be expected to underestimate the prevalence. Clinical studies will not be much better unless they are done on a clinic population which is first of all well described in terms of selection factors, and secondly follows retarded children longitudinally. The importance of epilepsy is that it can be controlled by medication, and untreated epilepsy can lead to a deterioration of mental functioning.

For the population of severely retarded children there are 4 epidemiologic studies quoted in the review by Abrâmowicz and Richardson[8] which allow calculation of percentages of the population with epilepsy. The definition of epilepsy is not clear for all studies but in most cases a child who has had less than 4 convulsions or convulsions confined to early infancy are not classified as epileptic.

The following table shows the percentages found:

Table 3: Epidemiological Estimates of the Prevalence of Epilepsy in the Severely Retarded

Author	Place	% of severely retarded with epilepsy
Drillien	Edinburgh	9 *
Lewis	London	9
MacDonald	Quebec, Canada	11.6
State Health Board	Oregon, U.S.A.	17.3
	mean	11.7

* Drillien described only those in whom epilepsy was the only major handicap.

In reference to this table it should be noted that Drillien included only those children in whom epilepsy was the only major handicap besides mental retardation. It is clear that her estimate is quite low. If we make the conservative assumption that 20%** of her children who have cerebral palsy or multiple handicaps also have epilepsy, we can add

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** based on figures of 25 to 35 percent prevalence of epilepsy in cerebral palsy given in standard pediatric textbooks.

another 7 percentage points to this estimate bringing the total mean to around 13.5%. This would seem to be a minimum figure for this group of severely retarded children and is much higher than the 4% estimate arrived at by Conley[4] by calculating backwards from the population of epileptics reported to have mental retardation and the prevalence of epilepsy in the general population. The most likely explanation is that the data available to Conley on IQ in epilepsy were derived from biased samples.

What appears to be missing in the literature is a good longitudinal clinical study to corroborate this prevalence. The only one which comes close is that of Drayer[14] in 1958 who reported a figure of 24% for epilepsy in a random sample of a large mentally retarded population followed clinically. However, we do not know his definition of epilepsy nor the proportion of his population which was severely retarded.

For the mildly retarded there is very little data. The figure given by Beck[6] of 6.2% is based on a small clinical sample and an unclear definition of epilepsy. This figure is very likely high at least in terms of the definition criteria stated above. Drillien on the other hand, in her epidemiological study in Edinburgh, gives a figure of 10.6% epilepsy in the mildly retarded. However, as mentioned, she only considered cases where the only major handicap other than retardation was epilepsy. If we again assume that about 20% of cerebral palsy

and multiply handicapped children will have epilepsy too, we can add 4.7% bringing the estimated total to 15.3%. However, as already noted, Drillien reported an unusually low prevalence of mildly retarded children, and this probably biases her figure in an upward direction. On balance it is perhaps best to accept a figure of around 6%.

Cerebral palsy is a condition which can be diagnosed quite reliably on clinical examination, and therefore any study which includes examination of the children ought to give a reliable estimate of the prevalence. Three[7, 16, 17] of the best twenty epidemiological studies analyzed by Abramowicz and Richardson[8] give figures which allow calculation of rates of cerebral palsy in severely retarded children. In each of the studies the children were either examined or their hospital records which included reports from neurologists were examined:

Table 4: Epidemiological Estimates of the Prevalence of Cerebral Palsy in the Severely Retarded

Author	Place	% of severely retarded with cerebral palsy
Drillien	Edinburgh	22.9
MacDonald	Quebec	13.0
State Health Board	Oregon	15.8
	mean	17.2

For the mildly retarded, the study of Drillien et al is the only one which is available. This figure of 6.7% is quite possibly high for reasons previously discussed. Conley[4] calculates an expected figure

of 2% for the entire retarded population by analyzing the literature from the point of view of the prevalence of retardation in cerebral palsy, and the population prevalence of cerebral palsy. It seems likely that this estimate is low, and it is perhaps reasonable, though inaccurate, to accept a figure between 2 and 6.7%, say 4% for the mildly retarded.

In addition to neurological services for the two conditions mentioned, neurologists are frequently required for diagnostic studies in retarded children.

II.5 Orthopedic Problems

There are very few papers in the literature which give figures regarding the orthopedic needs of retarded children. It is well-known to clinicians that the needs are high and that they change throughout life. Some congenital deformities require correction in early infancy. Neurological conditions such as cerebral palsy result in changing deformities and functional abilities which often require orthopedic procedures later in life. Deformities of the spinal column are likely to arise in late adolescence. The director of the Cerebral Palsy Unit at Montreal Children's Hospital says that virtually all cerebral palsy children need some orthopedic intervention during their life, and that beyond the age of ten, about half of these children require ongoing orthopedic care.* Since cerebral palsy is not the only condition of retarded children requiring orthopedic care, it is impossible to estimate the true need for orthopedic care in the absence of a good clinical study. The study of Smith[15] gives an estimate of 17% of institutionalized retarded children with orthopedic conditions. His population is likely primarily severely retarded, and it results from a single examination, and therefore probably represents a minimal estimate. There is no figure available for the mildly retarded.

* Larson C.P. Personal communication.

II.6 Visual Problems

Blindness is a condition which is relatively easy to diagnose even in the retarded, and therefore epidemiological studies ought to give reasonable estimates of the prevalence. Among the severely retarded MacDonald [16] found a rate of 2.8% for blindness or near blindness. Smith [15] found that 8% of institutionalized children had "vision loss" which is not clearly defined. MacDonald's rate probably comes the closest because it is based on a geographic population. Most of the other epidemiologic studies do not give figures for blindness.

Other ophthalmological disorders are also prevalent among the retarded. Two clinical ophthalmological studies give figures for other types of eye defects amongst large populations of children assessed at special clinics for the retarded. Edwards et al [19] examined 728 consecutive children of average age 6.4 years in Louisville, Kentucky and found that 48% had an eye abnormality. Their clinic population is skewed towards the severely retarded, but they give a breakdown of findings by IQ, and interestingly, they make an estimate of whether the eye defect is likely to be related to the developmental handicap in their children (although they do not say how they arrive at this conclusion). The following table is extracted from their data:

Table 5
Ophthalmological Problems in Children Assessed for Developmental Delay*

IQ	≤20	21-35	36-50	51-70	70-85	>85
N of patients	47	72	117	171	118	63
Problem present	34 (72%)	33 (46%)	57 (49%)	89 (52%)	63 (53%)	17 (27%)
Possibly related to handicap	17 (36%)	9 (12.5%)	16 (14%)	18 (11%)	9 (8%)	2 (3%)

*from Edwards et al,[19] 1972

Several things are noteworthy in this table. Firstly the rate of eye findings appears to be fairly consistent across all levels of retardation including the borderline group, and is approximately twice the rate for children with normal IQ's in the study group. When it comes to estimating whether the eye problem has something to do with the handicap, there is a clear relationship with the degree of developmental handicap as expressed in terms of IQ. Even in the mild group they estimated that the eye problem had something to do with the degree of handicap in 11% of the cases.

A similar study by Bankes[20] in London, based on a population of 171 children with a mean age of 4.2 years gave a figure of 77% with eye problems. The main difference between these two studies was that Bankes found much higher rates of refractive error (52%) and strabismus (40%) than did Edwards (18% and 17% respectively). Other

types of ocular abnormality such as cataracts, retinopathy and syndrome-associated deformities were found in similar proportions in these two studies (about 15% altogether).

Thus the need for ophthalmological care amongst the retarded is likely present in at least 50% of all types of retarded children at about the point of school entry. Since many of these problems change and other new ones (particularly refractive errors) develop around adolescence, the lifetime need for ophthalmological care probably approaches 60 or 70% at least. It could be argued that all retarded children should be examined by an ophthalmologist at least once.

II. 7 Hearing Problems

Hearing problems are the only type of otolaryngologic abnormality which has been studied in the retarded. It is well known that sensory deprivation in the form of severe hearing loss can cause developmental delay. However, deafness, unlike blindness, is not easy to diagnose and is sometimes missed even when severe. Thus epidemiologic studies may underestimate its prevalence.

For the severely retarded, only one of the epidemiological studies assessed by Abramowicz and Richardson[8] as meeting reasonable levels of accuracy, give figures for deafness. MacDonald[16] found "grossly defective hearing" in 2. 4% of severely retarded children in Quebec. Earlier studies such as that of Levinson[21] in Maine gave a much lower figure of 0. 34% severe hearing loss and 1. 6% significant hearing loss across the entire population of retarded children. However this study has many problems and did not meet the requirements of Abramowicz and Richardson. It is also based on reported data of existing medical services, and is therefore probably an underestimate.

No epidemiological studies could be found which give figures for deafness among the mildly retarded.

There is one clinical study of hearing loss which is worthy of note, and that is the study of Lloyd and Reid[22] who examined an entire institutional population very carefully with puretone audiometry

in a soundproof room. They were able to examine 75.5% of the 638 children and they found that overall there was a 13% rate of significant hearing loss, using their most stringent criterion of 20 decibels loss in both ears at one or more frequencies between 250 and 4000 Hz. The rates varied from 4% in the mildly retarded to 28% in the profoundly retarded (IQ < 20). The types of hearing loss found were conductive (45%), sensorineural (30-35%), and mixed (15%). In a further 5-10% the type could not be established. Many of the hearing problems uncovered by Lloyd and Reid[22] would be classified as mild or mild to moderate, but nevertheless they would be treated if they were to be diagnosed in "normal" children. At present there is a debate in the literature on the relationships between mild hearing loss and developmental delays. Much of the evidence in both directions centers on studies of otitis media which causes mild conductive hearing loss in children. One school of thought argues that mild hearing loss in children during the years of language aquisition leads to developmental delays. The evidence around this theory is reviewed by Leviton[23]. No conclusions are warranted on the basis of present knowledge. However, in the absence of conclusive data, mild to moderate hearing loss should be diagnosed and treated in the retarded population at as early a stage as possible.

On the basis of the data available it is not possible to arrive at very good estimates of the prevalence of hearing loss in the general

population of retarded children. MacDonald's [16] study is the only one which considers both institutional and non-institutional populations and it refers only to severely retarded. Development of new techniques such as the use of auditory evoked potentials may make testing of the retarded population easier. With present techniques it requires a lot of patience and perhaps a degree of specialization.

II. 8 Speech Disorders

Speech therapy is a separate paramedical discipline which is essential for service to the retarded. In the epidemiological studies revie wed by Abramowicz and Richardson[8], two gave figures for speech problems among the population of severely retarded children. The Oregon study[17] gave a rate of 50% and the Wessex study of Kushlick and Cox[24] estimated about 40%. A clinical study of 40 institutionalized retarded people (probably severe) by Jaslow and Spagna[29] showed a rate of 60% and all had received minimal or no intervention. The rates of speech disorders in the mildly retarded are unknown, but anecdotal evidence suggests they are prevalent.

II. 9 Psychiatric Disorders

Psychiatric disorders cover a multitude of symptoms. It is generally acknowledged that behavioural problems are very common among the retarded. However data are necessarily subjective because the concept of "normal behaviour" even for people of average intelligence is difficult to define.

Epidemiologic studies usually put the prevalence of "important" behaviour disorders among the severely retarded at between 10-15%.

Clinical studies of the retarded frequently suggest much higher levels of psychiatric disorders. Webster[26] was one of the first to present numerical data, from a child development clinic in Boston. He reviewed 159 children aged 3 - 6 in a sample which contained 13% IQ< 70, 50% IQ 50-69 and 37% IQ 20-49, and is therefore skewed towards the severely retarded. He could not rate a single child as normal. 35% of the children had mild disturbances of behaviour which he called the primary psychopathology of the retarded. He attempted to describe this by saying that they had impaired quality of emotional development consisting of poor modification of impulses, poor reality orientation and poor object relations in addition to some features of autism, repetitiveness, inflexibility, passivity and simplicity of emotional life. Superimposed upon this, according to Webster, was psychopathology of a moderate nature in 48% and of a severe nature in 17%. This latter figure corresponds nicely with

disturbances reported in the epidemiological studies.

Menolcascino[27] examined 616 children under the age of eight, evaluated for mental retardation at a psychiatric institute in Nebraska. His sample was skewed towards more severely retarded children and towards lower socio-economic status. He found that 31% of these children could be given a psychiatric diagnosis. More importantly, he pointed out that 6.5% of the total had primary psychopathology without mental retardation, drawing attention to the importance of psychiatric evaluation in the initial diagnosis of mental retardation.

The study of Birch[6] was both a clinical and epidemiologic study. All the retarded children identified were examined psychiatrically. They found an overall rate of psychiatric disturbance of 38% in the administratively ascertained children. However the rate was 52% for the severely retarded and 34.7% for the mildly retarded. Children with neurological problems were much more likely to have behavioural disturbances. This particular study probably gives the most reasonable estimate we have to date for a community-wide population. Note however, that there were an equal number of mildly retarded children who were not administratively ascertained by the schools as being retarded, and therefore received no psychiatric evaluation. These children are almost certainly likely to have a lower rate of the acting out type of behaviour disorder, since

that is an important reason for ascertainment of retarded children in schools. They could however have just as many internalizing-type disorders. It seems likely though that the true figure for the mildly retarded population is somewhat less than 34.7%.

While it is clear that many retarded children are seriously emotionally disturbed, it is likely that the parents of most retarded children could benefit from professional counselling as the child's development proceeds, even in cases where pathology is mild. This can be done by primary care physicians, nurses, social workers or psychologists (both behavioural and educational). There is a need for a multidisciplinary approach to such counseling, with good coordination of services.

II. 10. Physical Growth and Nutrition

There is an excess of physical growth retardation in all groups of retarded children. It is not clear how much of this is due to nutritional problems, and how much is intrinsic in the nature of the pathogenesis of retardation.

Kugel and Mohr [28] provide the most extensive study to date of physical growth in retarded children and it is based on a non-institutional population evaluated in a child development clinic. 811/879 referals were studied. They found an increase in linear growth retardation below the 17th percentile which ranged from 44% in the mildly retarded up to 68% in the most severe group. The relationship appeared to be linear. About 10% of the children were significantly underweight for their height. MacDonald [16] in her community-wide study of severe mental retardation in Quebec found 51% with linear growth below the 5th percentile for age.

Jaslow and Spagna [29] draw attention to the nutritional problems of retarded children in an institution. They studied the entire medical history of the first 50 admissions and found that 92% had had some nutritional concerns during infancy and 24% had had growth failure. They noted that none had been seen by a nutritionist. At the time of entry into the institution (mean age not given), 69% were growth retarded, 28% had bizarre eating habits and 12% had mineral deficiency. 28% were still using the bottle at ages between 4 and 27

years.

Clearly the need for good nutritional advice is essential throughout life for the severely retarded, and this requires the support of trained nutritionists. The needs of mildly retarded children are probably less acute but nevertheless significant.

II.11 Dental Care

There are no data in the epidemiological literature on dental problems in retarded children. The closest any study comes to looking at this problem from a community-wide perspective is the study of Snyder et al[30] who attempted to examine all the 244 known retarded children in 5 counties in Minnesota. Unfortunately, due to incomplete locating and non-response, they finally examined only 47% of these children. The sample had a mean age of 9.4 years and a mean IQ of 57, which suggests that the population was probably primarily mildly retarded. The main findings were that 66% had periodontal disease and that the caries present in the retarded were much less likely to have been treated than those in the normal population. In the age group from 5-9 years, only 3% of the damaged tooth surfaces had been repaired! Malocclusion was present in 48%. Oral hygiene practices were very poor (58% used a toothbrush less than once a week). 37% had never seen a dentist. They estimated that 23% of the children would require general anesthesia for repair of their teeth. The authors also surveyed dentists in the area and found that they would be generally interested in learning about the care of the retarded. They felt that some of the barriers to good care were on the parents' side because they were afraid of causing a fuss or because they had financial problems.

Jaslow and Spagna[29] found a similar prevalence of periodontal disease in 50 consecutive admissions to an institution (i.e. 60%). They also noted the lack of preventive dental care, and drew attention to the number of cariogenic reinforcers used in behavioural modification programs for the retarded, pointing out the need for better coordination between professionals.

II. 12 Medical Problems of the Educationally Backward, Non-Retarded Child

As in the previous sections, the problems addressed in this paper are primarily the more or less "traditional" types of medical problems related to organic disease and physical deformity. However, the most important needs of the parents of these children are likely to be in the social and emotional sphere and as Pless[32] has pointed out, these are frequently unmet by traditional medical services.

As discussed earlier, the children who experience educational failure do not represent a homogeneous group. They probably include at least four important subgroups: 1) mentally retarded, 2) socially and environmentally deprived children, 3) children with specific learning disabilities and 4) children whose problems are primarily psychiatric. However, the vast majority of such children will present with difficulties in reading, and this may be used as a marker to identify these children as suggested by Rutter et al[33] in the Isle of Wight study.

This is the only comprehensive population-based study of educational backwardness available. The findings suggest that educational backwardness defined on the basis of reading skills 28 months below chronological age, has a prevalence rate of about 80 per 1000. From validation studies they suspect that this is a slight underestimate of the true prevalence.

Differences in neurological and general medical problems were examined and compared with controls for the intellectually retarded, and the group of children with specific reading retardation (i.e. a specific learning disability).

No statistically significant differences were found for any of the neurological or medical problems studied. The following table represents an extract of some of these results.

Table 6
Problems found in Isle of Wight Study in Children with Intellectual and Reading Retardation

Problem	Mentally Retarded (N = 56-59)	Specific reading Retardation (N = 85-86)	Controls (N = 145-147)
Neurological			
Possible	20.3	18.6	13.0
Definite	33.9*	0	0
Epilepsy	16.4*	4.8	1.4
Hospital Admissions 3 or more	12.9*	7.1	2.8
Bronchitis 2 or more times in past year	14.5*	1.2	4.1
Chest illness causing confinement to house, past 3 years	17.0	16.7	11.6
Underimmunized	44.4*	32.9	22.1

* Significantly different from controls (p .05)

Adapted from Tables 5.1 and 6.2 in Rutter M. et al "Education, Health and Behaviour" 33

Several comments are relevant about these findings. Firstly, specific reading retardation probably indicates the least socially deprived group of the educationally backward children. Secondly,

the numbers in all groups are relatively small. Rutter et al[33] found no significant difference in health problems between the specifically reading retarded and the controls, but note that for almost all the problems studied, there is a biological gradient with increasing prevalence from control group to mentally retarded group. It seems likely that there is considerable possibility of a type II or Beta error in saying that there is not an increase in medical problems among the specific reading retarded group. When applied to populations larger than the Isle of Wight (approximately 95,000), the numbers could be important in terms of health care. Furthermore, we know little about these problems among the children who have other types of educational backwardness which are equally prevalent in the general population.

Emotional and behavioural disorders were found to be much more prevalent in both the intellectual and specific reading disability groups study by Rutter et al[33] by a factor of 3-4 times. The prevalence was similar in both of the handicapped groups and ranged between 30 and 40%. Antisocial behaviour was present in 45% of boys with specific reading disability.

Other studies of educationally backward children and their medical problems are surprisingly rare. A study by Herzig et al[34] which is often quoted as finding increased neurological findings of both hard and soft nature in children educationally designated as

brain damaged, is very difficult to relate to any of the population divisions being considered in this review, because the population which they describe likely encompasses a lot of non-retarded children.

A longitudinal study of a group of children from kindergarten to grade 6 by Galante et al[35] made an effort to relate minor physical abnormalities and birth history, in addition to some social factors, to underachievement in school at the grade 6 level. There was a 38% loss of subjects during the course of the study, and no tests of statistical significance appear in the article. Nevertheless, the authors suggest that birth history, sex (male) and position in the family (other than first) appear to be important predictors of who will be an underachiever at grade 6. They also suggest that eye muscle inbalance (i.e. strabismus) is a predictive factor.

Waldrop et al[36] examined "hyperactive" children in elementary schools and found that minor physical abnormalities were more common in male hyperactives than controls. The same was not true for females. Hyperactive children, of course, are not all educationally backwards, but many of them are. The study was performed on small numbers of children (12 to 34 in each group). The types of minor abnormalities found were generally the sort that result from genetic or intrauterine etiology such as low set ears, simian crease and high palate, to name only a few. Although this study is often used in developmental assessment of

preschool children, the results have never been verified in a larger study. If they are valid they would not only tell us something about the pathogenesis of hyperactivity in boys, but would also warn us that these external and superficial abnormalities could very well be associated with more serious internal abnormalities.

In summary then, very little is known about the health of the large group of educationally backward children who are not intellectually retarded by IQ measures. Studies suggest that the prevalence of traditional medical problems is only slightly higher than in the general population. However the Isle of Wight study demonstrates clearly that this group has a lot of behavioural and psychiatric problems. Since this group is the largest group of educationally handicapped children in the population, a better data base on health problems and health services for these children is highly desirable from a public health point of view.

II.13 Provision of Care to the Mentally Retarded and Educationally Backward

Corbett[37] traces the history of development of services for the retarded in Britain and other countries from Ancient Greece where handicapped infants were destroyed, through the dark ages where retardation represented possession with a devil, to the development of training and custodial institutions in the 19th and early 20th centuries. It is only in the past twenty years that the trend in western countries has been towards more community based care, first with special education, but more recently with a trend towards "normalization"[38] defined as "making available to the mentally retarded patterns and conditions of everyday life which are as close to the norms and patterns of everyday society as possible".

A good deal of lip service has been paid to the need to develop multidisciplinary services which are well coordinated. No one individual can provide all the services needed by a retarded individual. The WHO Technical Report of 1968,[5] in discussing the medical aspects of the care of the retarded, recommends that attention should first be paid to an etiological diagnosis, and then to complete evaluation and treatment of all other physical and mental problems, and that this treatment should continue throughout his life. They mention all of the special services listed in Table 8. The report also discusses the services needed in the fields of education, vocational training and social welfare, and legal barriers to acceptance of the mentally

retarded in the community. Improved training of all personnel involved with the retarded was recommended. Ministers of health, social welfare and education were urged to work together to develop coordinated services. Financial assistance to parents was recommended.

Some parts of the developed world have made more progress than others in providing such services. They are most highly developed in Scandanavian countries. In the U.S.A. great impetus was given to the development of programs in the early 1960's when the President's panel on mental retardardation was set up by President Kennedy. The results are reviewed by Hormuth,[39] and Brewer and Kakalik[44]. A number of specialized diagnostic clinics for retarded children were established, in association with university teaching centres, and these were linked to Maternal and Child Health Services, and funded federally. Teaching and Research Units were established. Clinics were meant to link up with primary care resources in the community. A number of programs aimed at the prevention of retardation were started. Although the success of some of these programs in achieving individual goals is clear, there is still a demonstrable lack of coordinated services for the retarded. Perhaps the most positive result is that a body of knowledge about the subject has been created, and a group of specialists in the field of retardation has evolved. In Canada there has been no such national effort and many provincial health authorities

have been slow to develop such services.

Interestingly, there have been relatively few studies which have looked at the nature of services actually received by handicapped children and their families. Those studies which do exist suggest that most parents are dissatisfied with the services they receive from physicians[40-44, 32] in proportions ranging from 50 to 66 percent of cases. They are particularly dissatisfied with the attention paid by physicians to the "non traditional" needs of the parents and children, such as emotional support, behavioural and developmental counseling, speech therapy, and day to day practical problems. Many parents give up on medical services early in the course of their child's development because of this dissatisfaction. The only Canadian work of interest in this area is the CELDIC[52] report of 1970 which is the work of an investigation conducted under sponsorship of a number of voluntary organizations for mentally retarded, emotionally disturbed, learning disabled, and crippled children. The report is not a scientific document, but as an indicator of dissatisfaction of parents of children disabled in these areas it is useful. In the report the medical model and the medical profession are particularly damned because of their failure to deal with the real needs of the parents and child. It called for major changes in the structure and organization of care for this all-encompassing and difficult to define group of handicapped children, removing the physician from his

key role in the relationship. Very little action seems to have resulted from this report.

Pless[32] argues that it is difficult to rationalize the separation of care of different types of handicap when similar problems are presented by both physical and mental handicaps, and many children with one type also have the other. Whether specific learning disabilities should be included as a handicapping condition if a systematic method of care is to be designed, is a matter for conjecture. It seems likely from earlier sections of this review that their needs for traditional medical services are only slightly greater than those of the general population of children. However their need for psychiatric services and other forms of counseling and educational help are equivalent to those of the retarded, and this group may comprise as much as 10% of the school population.

Brewer and Kakalik[44] performed what is to date the most comprehensive North American review of services to handicapped children. This study pertains to the United States, but there is little evidence to suggest that services are any better coordinated in most parts of Canada. The conclusion of their study was that the enormous amounts of money spent on various programs for handicapped children in the U.S. was not producing the kind of care that was necessary. They called for a reorganization of services for handicapped youth with the creation of Regional Direction Centers which would coordinate

TABLE 7

Proposed Staff Composition for Regional Direction Services for the Handicapped*

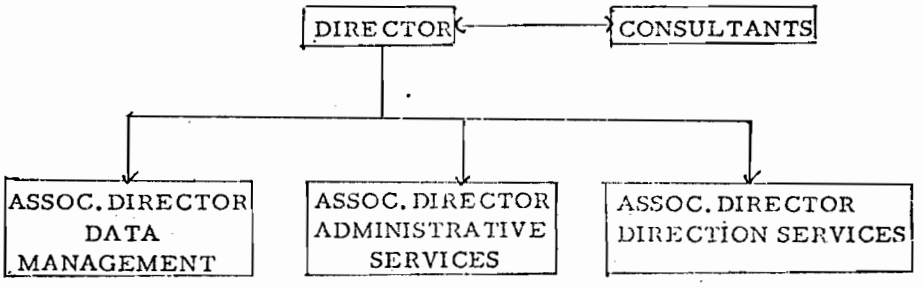
DIRECTOR - A physician

ASSOCIATE DIRECTOR/DATA MANAGEMENT - A data specialist
ASSOCIATE DIRECTOR/ADMINISTRATIVE SERVICES - a skilled administrator
ASSOCIATE DIRECTOR/DIRECTION SERVICES

SPECIAL EDUCATOR
VOCATIONAL REHABILITATION SPECIALIST
SOCIAL WORKER
PUBLIC HEALTH SPECIALIST
PSYCHOLOGIST
DIRECTION COUNSELORS
DATA MANAGEMENT TECHNICIAN
PARENT COUNSELORS (Volunteers)
CONSULTANT SPECIALISTS ON PARTICULAR HANDICAPS
CONSULTANT LAWYER

*From Brewer C.D. and Kakalik I.S.[44]

FIGURE 1



Organigram for a Regional Direction Center for the handicapped as proposed by Brewer and Kakalik[44]

the entire gamut of services required by handicapped persons, establish outreach programs, maintain a data system, foster client participation in the Direction Service, and ensure that comprehensive services are provided to all handicapped youth in the region. In addition it would act as an advocate and spokesman for the handicapped. In other words, such Direction Centers would take on roles which have been traditionally those of public health, educational and social services and voluntary groups. Table 7 shows the type of staff proposed by Brewer and Kakalik for a Regional Direction Center, and Figure 1 is an organizational chart of the administrative structure proposed. In their 1979 report they do not make specific recommendations on the size of the population which should be served by such a center. In their 1974 report[45] they were suggesting such centers to serve only blind and deaf children for a population base of 1-3 million. Both Brewer and Kakalik[44, 45] and Conley[4] make fairly convincing arguments that better organization of high quality services for the handicapped or retarded is likely to be cost beneficial in the long run, both because of money saved on inappropriate use and duplication of services, and in the prevention of secondary complications among the handicapped. Brewer and Kakalik[44] also argue that the advocacy role of Regional Development Centers may lead to opportunities for prevention of handicap in the future. The only important negative aspect of such centers is the concern that

many people have about the effects of labelling[46] children with a specific handicap. However these children are generally already labelled by either the medical profession or the education system, and to have them labelled but without coordinated help seems inappropriate.

TABLE 8

BEST ESTIMATES OF MEDICAL AND PARAMEDICAL SERVICES REQUIRED BY MENTALLY RETARDED AND EDUCATIONALLY BACKWARD CHILDREN

Type of Problem	Handicap: Severely Retarded (IQ < 50) %			Handicap: Mildly Retarded (IQ 50-60) %			Educationally Backward %	Types of Studies Used	Services Required
	Min	Max	Best Guess	Min	Max	Best Guess	Best Guess		
1. Neurological									
Any	45	73	60	26	67	26	?	C, E, I	P, N
Epilepsy	11.7*	24	20	6.2	15.3	6	2-4	C, E, C&E	P, N
Cerebral Palsy	15.8	22.9	17	2	6.7	4	?	C&E	P, N, OR, PT, R
2. Orthopedic	17	-	?	-	-	?	?	I	OR, PT, R
3. Eye Problems									
Any	52.5	77	65	52	52	52	52	C	O, Opt., RN
Blindness	2.8	2.8	2.8	-	-	1	?	C&E	O, Special, T
Refractive errors	no figures by IQ - Avg. = 40%						?	C	O, Opt., RN
Strabismus	" " " " - Avg. = 25%						?	C	O, Opt.
4. Hearing Problems									
Deafness	0.3	2.4	2.4	-	-	?	?	E	A, Ent., P, SP
Mild-moderate loss	-	20	20	-	4	4	?	I	A, Ent., P, RN, SP
5. Behaviour									
Severe	12.5	17	15	-	-	?	?	C, E	P, Psy., Psychol., SW T, RN, G. C.
Any psych. problem	-	52	52	-	34.7	34.7	45	C&E	P, Psy., Psychol. SW
6. Growth retardation			5XN			2XN	?.	C	P, Nu, RN
7. Nutritional		92	92	-	-	?	?	I	P, D, Nu, DH
8. Dental			100			100	100		P, SP, RN, T
9. Speech	40	60	50		-	?	?	E, I	

*Represents mean of 4 epidemiological studies

KEY

Types of Studies: C=clinical E=epidemiological I=institutional

Types of Services: A=Audiologist D=Dentist DH=Dental Hygienist ENT=Otolaryngologist GC=Guidance Counselor N=Neurologist Nu=Nutritionist O=Ophthalmologist Opt=Optician OR=Orthopedic P=Primary Care Psy=Psychiatrist Psychol. =Psychologist PT=Physiotherapist R=Rehabilitation Specialist, RN=Nurse SP=Speech Pathologist SW=Social Worker T=Teacher (incl. specialist)

II. 14 Summary

Children with mental retardation form a large part of the overall group of handicapped children. Educationally backward or learning disabled children are also handicapped. There is a very high burden of "traditional" medical problems amongst the retarded, which increases with the degree of retardation. The educationally backward children probably have only a slightly increased prevalence of traditional problems. Both these groups however, share an equal, and very high need for social, psychiatric, educational and vocational services. These services are traditionally obtained in multiple settings. The literature suggests that there is a need for much improvement in the coordination of these services.

Table 8 provides a summary of literature estimates of some health problems of the retarded.

SECTION III

METHODS

III. 1 The School Records

Under ideal circumstances, much of the information sought in this study should have been available from school health records. However it was discovered early in the planning stages that this would not be possible. Records at three schools were examined randomly and found to be inadequate. Due to reorganization of school health services, records from the old municipal health service had not all reached the schools or even the DSC's to which the children belonged. Records which were available were obviously incomplete. In one school (no. 3) the nurse informed us that the parents had almost uniformly refused to fill in the questionnaire regarding health sent out by the school at the beginning of the year. At school no. 4 the records were reviewed on 162 pupils. 17 of these had no chart at all, and 93 had charts which were more than 2 years old without updating and were therefore considered inadequate. Only 51/162 pupils had charts which were useful.

On the basis of this information it was decided that a questionnaire survey would be the only way to get the information needed.

III. 2 The Questionnaire Design

A questionnaire was designed consisting of 20 questions in total with 64 subdivisions in all. The questions were nearly all yes-no type answers, although parents were asked to write in names of doctors, their educational level and their occupation. There was one open question at the end where parents were asked for comments or suggestions about school health programs. Several questions were asked about primary and specialist care. Behaviour problems were examined by five specific questions about behaviour, control of temper, ability to make friends, sleeping and enuresis. Eight specific activities of daily living were checkedand parents were asked about the general level of ambulation of the child (i. e. wheelchair, limited or normal). They were asked about six chronic conditions of childhood (asthma, allergies, epilepsy, heart disease, cerebral palsy, and congenital defects) and parents were given an open space to list any other medical problems. For those with problems parents were asked where they obtained treatment. Patterns of emergency care were determined with one question only as a gross indicator ("If your child became very ill with cough and fever at night or on a weekend, where would you go to get treatment?"). One question was asked about medication use and parents were asked whether the child wears glasses or a hearing aid. Parents were also asked whether the child had had a general medical check-up in the last two years. This

question was asked both to verify the level of involvement with a primary care physician in those cases in which there was one, and to allow those without a primary care physician to indicate if they were obtaining some sort of general medical care for their child. If they had a dentist, parents were asked whether he had seen the child in the past year.

In addition to these questions, the parents education level, occupation and social welfare status were asked with the proviso that this information would remain confidential. Parents were asked a hypothetical question about whether they felt there should be more involvement of professionals in the school health program, and whether the child was learning enough about how to take care of his/her own health.

The parents were given the option of having the information kept completely confidential, or of having the medical part of the questionnaire transferred to the school nurse.

The questionnaire was then translated from English into French, Italian, and Portuguese. In each language it consisted of two sides of 8 X 14 inch stationery. After pretesting it was found that most parents required approximately 15 minutes to complete it and it appeared to be reasonably clear in all languages. The translations were retranslated back into English by a second person, and they came out almost exactly the same as the original. Therefore it was decided to proceed with distribution. There proved to be one previously undetected

complication with the French translation. When coding the responses it became clear that a certain proportion of parents became confused in answering question 4, the check list of behaviour and activities. The question was prefaced by the sentence "Votre enfant a-t-il des problèmes ou des difficultés concernant ce qui suit?" Subsection (i) and (ii) are nouns and clearly related to the above statement. However all the subsequent sections use the participle form of a verb, and were clearly interpreted by some parents as being complete statements not relating to the above sentence. They were therefore answered in the reverse of what was intended by the questionnaire (e.g. s'habiller seul means dresses himself, and some parents answered yes meaning that he did dress himself, when in fact the questionnaire intended the answer yes to mean he had trouble dressing himself). Since the answer to the majority of questions in this section should have been no, it was easy to pick out the parents who had misinterpreted this question. This was verified by randomly calling a few parents, and our suspicion was always confirmed. These answers were therefore corrected.

Copies of the questionnaire in each of the four languages (which were colour coded) are enclosed as Appendices A, B, C & D).

III. 3 Sample Selection

For several reasons it was decided to confine this study to high schools in the region served by the DSC Montreal General Hospital. Firstly, the DSC was having a problem deciding what to do with their school health program for a large population of special education pupils at the high school level. Because it is the only English language DSC it had inherited the responsibility for providing school health services to three large, English language high schools for mentally handicapped children which lay geographically outside the boundaries of the DSC. Since these schools serve a largely inner-city population of low socioeconomic status, the school nurses were frustrated at finding a lot of neglected health problems among this group, and also at having a low completion rate for consultations which they requested the parents to make. One of the primary purposes of this study was to give the DSC some information on which to rationalize their school health program to this population. A second reason for choosing the high school population was that the special education program in many of the elementary schools was quite varied or even non-existent. Therefore it was felt that at the high school level, children with educational handicaps would have been more reliably identified.

In fact, high school in Quebec starts at grade 7, and continues through grade 11. This is therefore a somewhat younger population

TABLE 9
CHARACTERISTICS OF SCHOOLS STUDIED

School	Type of Special Education Students	Regular Stream	Language	Religion	Sex (%) M	Sex (%) F	% in Each Social Class I	II	III	IV	V	Single Parent Families (%) or Institution SPF.	Inst.	Response Rate (%)
1	Learning disabilities and slow learners	Y	Fr.	C	38.3	61.7*	0	1.8	3.6	15.5	79.1	25.2	4.2	69.6
2	IQ 50-80	N	Eng.	P	58.0	42.0	7.5	3.5	17.9	31.4	49.7	20.8	0.5	82
3	Slow learners	Y	Eng.	P	43.1	56.9	4.0	2.0	14.0	30.0	50.0	20.0	1.7	61.3
4	Slow learners**	N	Fr.	C	53.5	46.5	1.1	1.1	2.1	11.7	84.0	26.2	4.7	82
5	Trainably & Educably retarded IQ 40-60	N	Eng.	C	56.3	43.7	0	3.4	0	19.0	77.6	9.5	1.6	95.9
6	Learning disabilities and slow learners	Y	Fr.	C	48.1	51.9	0	0.8	1.6	10.7	86.9	31.3	1.6	51.1
					$X^2_{5df} = 15.9$ $p = .007$		$X^2_{20df} = 104.9$ $p < .001$					$X^2_{10df} = 22.1$ $p = .01$		

* School number 1 had special classes for girls only, but regular stream was sexually integrated
** School number 4 undoubtedly includes some children who are actually retarded

than the high school population in other parts of Canada.

There were 13 high schools which had special education classes provided by the school health program at the DSC- Montreal General Hospital. From these, 7 were selected to represent the large schools for educably retarded children, and the lower and middle socio-economic areas of the DSC. After considerable negotiation, one of these schools refused to participate because the members of the school parents committee felt that the information we were asking for was too confidential. Thus there were 6 schools in the sampling frame. The characteristics of these schools and their student populations are listed in Table 9. 2 schools had large regular stream populations in addition to smaller special education programs. The other 3 schools had special education programs only.

All the pupils in special education programs in these 6 schools were surveyed. The control group was smaller than the special education group, and consisted of a random sample from the regular streams of each of the 3 mixed schools, equal in size to the special education program enrollment of that school.

III. 4 Distribution of Questionnaire

Questionnaires were distributed in various ways depending on the school. In schools 2, 3, 4, and 6 initial distribution to children in special education took place in the classroom and responses were returned by the pupils to the school nurse to save on postage. Non-responders were mailed a second questionnaire 3 weeks later, followed by either a telephone reminder or a third mailing 3 weeks later in all schools except no. 6 for which permission to go ahead was granted too late in the school year to allow a third reminder. In school no. 1, all distribution was done by post because a conflict between the parents and staff forced the closing of the school for several weeks just at the time the survey was to begin. In school no. 5, the principal took a great interest in the survey and personally supervised the distribution of questionnaires at a parents night, and then had the school secretary remind the parents until virtually all the questionnaires were returned to the school office.

The distribution of questionnaires began at the end of March 1979, and terminated at the end of June 1979. Each pupil was assigned a number in order to preserve confidentiality, and the code was kept in a central log book by the part-time research assistant who helped with the project. Only the first name of the child was placed on the top of the questionnaire so that parents with more than one child in the school could identify the subject of the survey.

A letter which accompanied the questionnaire explained the purpose of the survey, and indicated to parents that the questionnaire was available in four languages. A copy of the English version of this letter is included as Appendix E. When questionnaires were being sent to parents of children in regular classes, a small tag was attached to the top of the letter indicating that children in normal classes had been selected from the school lists by a "scientific method," to provide a comparison for the children in special classes (Appendix F). This was done to reassure parents that not all the questions were likely to relate to their child, and thus alleviate potential discontent and non-response.

Another tag was affixed to the bottom of the letter when questionnaires were sent in several languages because parental language capabilities were not known (see also Appendix F).

The letter gave a telephone number that was included in the hope that parents who were unsure of the legitimacy of the survey would call for an explanation. This proved to be the case, and although no record was kept of the number of calls received, the research assistant and the principal author answered many calls, and undoubtedly this improved the response rate.

The letter sent with repeat mailings is included as Appendix G.

III. 5 Response Rate

1059 children were included in the survey (776 in special education and 273 in regular stream). The final overall response rate was 70. 9% with the response rate being 77% for children in special education and 56% for children in regular classes. The far right column of Table 9 lists the response rate for each school. The very low response in school number 6 probably reflects the fact that there was a lot of opposition to the survey among the school staff, and thus distribution was late, and only two mailings were completed with no telephone reminders. The very high response rate in school no. 5 reflects the personal interest of the principal.

III. 6 Assessment of Non-Responders

In order to control for non-response bias which might be particularly important in regards to health care utilization data, it was decided to complete the interview by telephone for a random sample of the non-responders. Schools numbers 1 and 2 were selected for this procedure because they represented both French and English, and because they were the first two schools in which the survey was completed, allowing sufficient time for telephone interviewing. A random sample of 68 non-responders was selected and the interview was completed by two trained interviewers, by telephone, for 51 of these non-responders, (75%). The reason for non-completion was inability to reach the family in all but one case. There was one refusal, thus confirming our impression that non-response was not usually deliberate.

III. 7 Coding and Analysis of Data

Coding of data was performed by two trained coders. A copy of the coding instructions is included as Appendix H. Most of the coding was straightforward. The previously mentioned interpretation of responses to question 4 parts iii) to Xiii) on the French questionnaire, was performed by the coders. In cases of doubt the author was consulted. When a specialist was named, the type of speciality was obtained from the Medical Directory of the Corporation Professionelle des médecines du Québec, 1978-1979 edition. Completion of box No. 59 required interpretation by the coders. An attempt was made to determine the proportion of single parent families and institutionalized or foster children in the sample even though these questions were not directly asked. Coders were instructed to code as a single parent family if there was a written comment to that effect, or if there was no information provided on the education and occupation of one parent or the other. Frequently the respondent would write unknown in the space beside occupation of the other parent, indicating probable separation. When information was provided about both parents it was assumed the family was intact. Obviously there can be error in both directions, but as a rough indicator of single parent families this method provides a reasonable approximation. The child was coded as institutionalized, when the respondent was a legal guardian or the name of an institution (centre d'acceuil) was pencilled in. The category "institutionalized"

includes foster care.

Coding of social class was entered in box No. 60 according to the Hollingshead Two Factor Index of Social Class, giving classes I to V. All of this coding was performed later by the principal investigator.

Random questionnaires were recoded by the author to check for error. Errors were found to be so infrequent that re-coding of all questionnaires was felt to be unessential.

The data set was entered on disc in the HP 3000 computer at the Montreal Childrens Hospital, and analysis was performed using the McMaster University adaptation of the SPSS program for Hewlett Packard computers.

SECTION IV

RESULTS

Table 10

Background Characteristics of Study Population

Characteristic	
Age ± S.D.	15.1 ± 1.5
Language Capability	
French	53.1%
English	43.6%
Italian or Portuguese only	3.5%
Father's Education (yrs.)	7.7 ±3.7
Mother's Education (yrs.)	7.4 ±3.1
Social Class (Hollingshead)	(%)
I	2.6
II	2.1
III	7.6
IV	17.6
V	70.5

IV. 1 Background Characteristics of the Population

The population studied had a mean age of 15. 1 years, was almost evenly split in language orientation of the family between French and English, had a typically low level of parental educational advancement, and more than 88% fell into the two lowest social classes on the Hollingshead Two Factor Index. (Table 10)

The population was readily divided into three levels of learning ability according to the class and school that they attended. The group of mentally retarded children attended schools 2 and 5. Slow learners and children with learning deficits attended special classes at schools 1, 3, 4 and 6, and normal children were selected from regular classes at schools 1, 3 and 6. This division however, led naturally to some differences in demographic variables between the groups (see Table 11). There were language, sex, age and social class differences between the groups. The statistical significance of these differences is of little consequence for the purpose of this study. The question is whether for the purposes of comparison of differences in health status and disease prevalence, these differences are important. Under the circumstances it was not possible to obtain a sample which provided equal distribution of these variables in the three groups. It was felt that these differences are not very important, with the exception of social class. Since one of the hypotheses was that there would be a greater burden of disease amongst the more retarded, and since the majority

Table 11

Background Differences between Groups

Group	I Retarded	II LD/slow	III Normal
Language	Eng	Fr	Fr
Sex	↑ ♂	↑ ♀	≈ eq.
Mean age ± S.D.	15.4 ± 1.5	15.0 ± 1.7	14.6 ± 1.5
Social Class % IV & V	77.4	94.7	92.7

of medical problems found have a higher prevalence in lower social classes (e.g. neurological problems, psychiatric disorders, birth defects), the fact that the retarded group was from a generally higher social class would tend to minimize the differences in medical problems found between the groups.

Table 12

Comparison of Responders and Non Responders on Selected Answers

Variable	Responders %	Non-Responders %	X^2	df	p-value
Primary Care M.D.	55	49	16.0	2	.0003
Institution	1	10			
None	44	41			
Medical Exam < 2 yrs ago	64	63	0.0004	1	.98
Limited Activity Rating	12	8	0.7	2	.71
Trouble Dressing Self	2	10	6.94	1	.008
Trouble Feeding Self	1	6	4.66	1	.03
Medical Problem	30	18	2.47	1	.12
Medication	14	4	2.88	1	.09
Uses Glasses	27	24	0.09	1	.77
Has Dentist	65	66	0.008	1	.99
Social Class* II and III	14	27	7.91	4	.09
IV and V	82	70			

*The trend was for slightly higher proportions of non-responders in classes II and III, and more responders in IV.

IV. 2 Responders vs Non-Responders

The 51 non-responders who answered a telephone interview were compared with the 700 who responded voluntarily in writing. Because of small numbers, the non-responders were not separated into the 3 groups based on learning ability, but the proportion of non-responders was approximately equal.

The background characteristics of the responders and non-responders were identical, and the only important difference between them was that non-responders were much less likely to have a primary care physician and were more likely to use an institution for care ($X^2_{2df} = 16.0$, $P = .0003$). The Chi-square values for some of the other comparisons are listed in Table 12. The pattern of seeking emergency care was also significantly different, but this probably results from the fact that the non-responders rarely had a primary care physician and therefore none of them would attempt to get emergency care from him whereas 4.8% of responders would. Over 80% of both groups would seek after hours care at a hospital emergency.

Because only the primary care utilization is different between responders and non-responders, the two groups were combined for further analysis.

Table 13

Medical Conditions Reported in the Three Groups

	Group 1 Retarded (N = 278)	Group 2 slow learners (N = 267)	Group 3 Normal (N= 168)	X^2	df	p
Any condition	92 (33.1%)	72 (27.0%)	38 (22.6%)	6.1	2	.05
Epilepsy	18 (6.4%)	12 (4.5%)	1 (0.6%)	8.7	2	.01
Birth defects	23 (8.3%)	2 (0.7%)	0 (0%)	30.8	2	.001
Cerebral palsy	6 (2.2%)	3 (1.1%)	0 (0%)	4.0	2	.15
Cardiovascular problem	7 (2.5%)	8 (3.0%)	2 (1.2%)	1.5	2	.45
Allergy	28 (10.1%)	22 (8.2%)	23 (13.7%)	3.3	2	.34
Asthma	4 (1.4%)	11 (4.2%)	7 (4.2%)	4.1	2	.14
Psychiatric problem	7 (2.5%)	6 (2.2%)	0 (0%)	3.1	2	.21

IV. 3 Medical Conditions Reported by Parents

28. 4% of the children in the entire sample were reported to have some sort of medical condition. Table 13shows that the proportion with medical conditions increases significantly with degree of intellectual handicap. Specific handicaps such as epilepsy and birthdefects also show significant increase in the more retarded groups. Cerebral palsy does not show significant differences between the groups because it is a very rare condition. However it too shows a linear trend towards a higher prevalence in the more retarded groups.

When epilepsy, cerebral palsy, birth defects and cardiovascular problems were combined together and defined as chronic conditions we found that one or more of these conditions was present in 16. 6% of group I, 7. 3% of group II and only 1. 7% of group III students ($X^2_{2df} = 30.5$, $p < .01$).

Where a medical problem of any sort existed (177 students) the parents were asked whether they felt that this problem interfered with their child's school work. 34% of the normal group, 47% of the slow learner group and 55% of the retarded group answered in the affirmative. While the numbers were too small for statistical significance, it suggests that health problems are more important for those in special education, and the type of problems reported clearly are more likely to cause problems with school.

Medication use seems to be relatively limited, with only 13. 5%

of parents reporting that their children required regular or frequent courses of medication. Antihistamine-decongestant medications were by far the most commonly used, with antibiotics second and anti-convulsants third. Only 5 children in the entire study were using stimulant medications. There were no significant differences between the three groups on their overall use of medications.

Table 14

Activity Limitations by Group

(percentages)

Activity*	Group 1 Retarded	Group 2 Slow	Group 3 Normal	p
dressing	5.7	0.7	0	.0001
feeding self	2.5	0	0	.004
getting around house	1.8	0	0	.02
getting around city	23.1	8.6	0	.000
toiletting	3.2	0	0.6	.003
running	6.4	2.6	0.6	.003
walking	2.1	1.5	0.6	.43
washing	3.9	1.5	1.2	.04
Parents' rating of activity+				
normal	85.0	91.4	97.8	.001
limited	15.0	8.6	2.2	

Chi square testing of statistical significance

*Activity here refers to self-help skills and ambulation, not to the increase in random activity which occurs frequently in special education students which is also known as hyperactivity.

IV. 4 Activity Limitations

A general question about activity limitations was asked of the parents, breaking activity down into 3 categories: normal, some limitation of physical activity such as limited sports, and confined to a wheelchair. 569 parents answered this question and 9.7% of them perceived their child to be limited to some degree. Only one child was confined to a wheelchair, a child from group 2. There was a significant increase in the proportion of children with limited activity levels in the retarded and slow learner groups (Table 14).

All of the limiting in individual activities of daily living and physical activities asked about were more common in the retarded group, except walking. Making their way around the city was the greatest problem activity with 23.1% of the retarded children having difficulty in this area (Table 14).

Table 15

Behavioural Symptoms by Group

Symptom	Group I %	Group II %	Group III %	X^2	df	p
Control of behaviour	29.0	25.7	9.5	24.1	2	.0000
Control of temper	30.6	36.3	18.2	16.4	2	.0003
Making friends	22.6	10.1	3.0	39.0	2	.0000
Sleeping	4.3	3.8	2.4	1.1	2	.57
Enuresis	4.3	6.6	1.8	5.8	2	.06
One or more symptoms or a psychiatric disorder	49.5	40.8	22.0	34.4	2	.0000

IV. 5 Behavioural Symptoms

Although there were only 12 children in the entire study who were listed as having psychiatric disorders, almost 40% were found to exhibit some behavioural symptoms. Table 15outlines these by group. Behavioural symptoms appear to be much more common amongst the special education groups, and more prevalent as the degree of educational handicap increases. Of the questions posed, only sleeping difficulties and enuresis fail to reach statistical significance, and these were both low prevalence symptoms.

The bottom line in Table 15 shows that almost half the retarded children have one or more of the symptoms listed or a psychiatric disorder, while less than one quarter of the children in regular class did.

Table 16

Health Care by Group

	Group I (%)	Group II (%)	Group III (%)	X^2	df	p
Primary Care Physician	57.6	53.1	57.3	3.2	4	.53
Institution	3.8	4.2	1.8			
< 2 Visits to Primary Care Physician in Past Year*	52.8	27.1	43.3	18.1	2	.01
Specialist	24.8	21.2	9.6	16.7	2	.01
Specialist Visit in Past Year**	57.1	71.4	85.7	7.1	2	.13
Specialist or Primary Care	64.7	58.1	58.4	3.1	2	.21

* Percentages apply only to the 373 with a physician

** Percentages apply only to the 140 children with a specialist

IV. 6. 1 Primary and Specialist Care

Primary care physicians included primary care pediatricians. Table 16 shows that there were no differences between the three groups as to who had a primary care physician. Only slightly over half the population has a nameable primary care source. When primary care was considered more stringently, including, in addition to naming a source of care, some evidence that the physician did health surveillance and maintenance acts (in this case administered vaccinations and weighed and measured the child regularly), and the physician had performed a general physical examination in the past two years, the total number with primary care dropped further to 44. 6%. Adolescents in group I were far more likely to have seen their primary care physician only once or less in the past year than those in the other groups.

Children in groups I and II were much more likely to be followed by a specialist than the children in the normal group. Neurologists (18%) were the most commonly mentioned specialists and orthopedic surgeons second (15. 8%).

The presence or absence of a chronic disease as defined by the five conditions specifically probed for made no difference whatsoever as to whether the child had a primary care physician (Table 17). However it was related to having a specialist for each of the 3 groups. The presence of a chronic disorder was also related strongly to

Table 17

Care Patterns of Children with a Severe Chronic Disease (Epilepsy, Cerebral Palsy, Heart Disease, or Birth Defects)

		Group 1 Retarded (N = 289)		Group 2 Learning disabilities and slow learners (N = 289)		Group 3 Normal (N = 173)	
		Chronic Disease		Chronic Disease		Chronic Disease	
		Yes	No	Yes	No	Yes	No
		48	241	21	268	3	170
Primary Care Physician	Yes	27 (56.3)	139 (57.9)	16 (57.9)	136 (51.3)	2 (66.7)	96 (57.1)
	Institution	19 (39.6)	92 (38.3)	5 (23.8)	117 (44.2)	1 (33.3)	69 (41.1)
		2 (4.2)	9 (3.8)	0 (0)	12 (4.5)	0 (0)	3 (1.8)
		$X^2_{2df} = .05$ p=.97		$X^2_{2df} = 5.1$ p=.08		$X^2_{2df} = .01$ p=.93	
Specialist	Yes	30 (62.5)	39 (16.9)	13 (61.9)	44 (17.7)	2 (66.7)	14 (8.5)
	No	18 (37.5)	192 (83.1)	8 (38.1)	204 (61.9)	1 (33.7)	150 (91.5)
		$X^2_{1df} = 45.8$ p= .001		$X^2_{1df} = 20.0$ p= .001		$X^2_{2df} = 5.8$ p=.02	
Specialist or primary care	Yes	39 (81.3)	148 (61.4)	19 (90.5)	149 (55.6)	3 (10.0)	98 (57.6)
	No	9 (18.8)	93 (38.6)	2 (9.5)	119 (44.4)	0 (0)	72 (42.4)
		$X^2 = 6.1$ p=.01		$X^2 = 8.3$ p=.0004		$X^2 = 1.6$	p= 0.2
Both		18 (37.5)	29 (12)	10 (47.6)	31 (11.6)	1 (33.3)	12 (7.1)

having either a specialist or a primary care physician, and to having both types of physician. However the more interesting and useful figures are the percentages. Fully 35.3% of the retarded children have neither type of care, including 18.8% of the children in the group with a chronic disorder. The differences between the groups do not reach statistical significance.

IV. 6. 2 Factors related to having a Primary Care Physician

From the point of view of a Community Health Department, it is interesting to ask what factors are associated with having a primary care physician for a deprived group of students like these. One factor which is clearly not related to primary care is the degree of educational handicap. Therefore, we considered all 3 groups together. Clearly the best predictor of primary care is whether the family answered the questionnaire or not, with non-responders being much less likely to have primary care, (Table 18). This may have some relevance for school health programs, as it might apply to health questionnaires which are sent out at the beginning of the year. Apart from response status, father's schooling, social class and the presence or absence of a medical condition of any sort are fairly strong predictors. In this study being female was also weakly associated with having primary care (Table 18).

Table 19 lists a number of variables which were unrelated to having primary care in this sample.

Table 18

Factors Related to Having a Primary Care Physician

Categorical Variables

Variable		%	X^2	df	p
Social Class		--	21.2	8	.007
Respondant			16.0	2	.0003
Medical Condition	Yes	65.3	12.9	2	.002
	No	57.2			
Sex	Male	51.1	7.1	2	.03
	Female	60.8			

Continuous Variables

Variable	Pearson's r	p
Father's schooling	.14	.0004

Table 19

Factors Unrelated to Having a Primary Care Physician

Categorical Variables

Variable	%	X^2	df	p
Language		11.0	6	.09
School	--	13.8	10	.18
Status (3 gps.)	--	2.0	2	.37
Psychological Symptoms	--	0.2	2	.92
Activity Rating	--	3.2	4	.53
Single Parent Family		2.2	4	.70

Continuous Variables

Variable	Pearson's r	p
Age of Child	-.02	.34
Mother's Schooling	.03	.20

Table 20

Pattern of Emergency Care

Place	Group I	Group II	Group III	TOTAL
Pediatric Hospital	95 (39.3%)	93 (39.7%)	38 (26.6%)	226
General Hosptial	109 (45.0%)	103 (44.0%)	73 (56.0%)	285
Other	38 (15.7%)	38 (16.3%)	32 (22.4%)	108
Total	242	234	143	619

$$X^2_{4df} = 8.69,\ p = .07$$

IV. 7 Pattern of Emergency Care

The pattern of help sought in an emergency situation was based only on one hypothetical question only. Table 20 shows the type of emergency care sought in the three groups according to the responses given by 619 parents who answered this particular question. It is clear that hospitals are the major source of after-hours care for this population. It is also interesting to note the relatively small proportion of care given for these adolescents at pediatric hospitals. Children in the two educationally handicapped groups seem more likely to seek care at a pediatric hospital.

Private physicians would provide only 3. 6% of this type of care and CLSC's (the local community service centres) would provide 10. 3%.

Table 21

Children having a Dentist by Group

	I	II	III	
Yes	186	147	122	455 (62.4%)
No	95	131	48	274 (37.6%)
Total	281	278	170	729

$X^2_{2df} = 18.8,\ p = .0001$

Table 22

Children who had seen a Dentist in the Past Year by Group

	I	II	III	
Yes	147 (52.3%)	113 (40.79%)	109 (64.1%)	369 (50.6%)
No	134	165	61	360 (49.4%)
Total	281	278	170	729

$X^2_{2df} = 23.8,\ p < .0001$

IV. 8 Dental Care

There were significant differences between the groups for having a dentist as shown in Table 21 with children in group 2 being much less likely to have a dentist than the other two groups. Both groups of educationally handicapped children were less likely to have seen a dentist in the past year than the normal children (Table 22).

The best predictors of who would have a dentist, considering the entire sample were in this case social class ($X^2_{4df} = 24.4$, $P = .0001$) and school attended ($X^2_{5df} = 24.0$, $P = .0002$). Having a medical condition of any sort was also related to having a dentist ($X^2_{1df} = 4.4$, $P = .04$). In contrast to the situation with physicians, neither response status nor sex correlated with having a dentist.

IV. 9 Use of Wheelchairs, Glasses and Hearing Aids

Only one child in the survey population was confined to a wheelchair, and this child was in the special education group (II). None of the schools were physically designed to make wheelchair ambulation easy.

The use of hearing aids was used as an indicator of the prevalence of significant hearing loss. Results showed that they were used by 7 children in the retarded group (2. 5%) and 3 children in the special class group (1. 1%) and by 2 children (1. 2%) in the normal group. These results were not statistically significant.

Glasses were used as an indicator of ophthalmological services utilized. Approximately 28% in each group wore glasses and there were no differences between the groups.

Table 23

Comments Regarding School Health Programs

School	Negative (N)	Positive (P)	Ratio ($^{N}/_{P}$)
1	26	2	13:1
2	23	8	2.9:1
3	10	0	
4	10	3	3.3:1
5	2	2	1:1
6	11	2	5.5:1

IV.10 Relevant Comments by Parents

The final space on the questionnaire was a space of seven lines where parents were invited to make comments or suggestions regarding the school health program. This type of open question is not particularly useful for statistical analysis, as it is likely that people with complaints will use it more frequently than those who are satisfied. The comments however, may give an idea of what parents feel is missing in the program. In total, 101 parents made comments which were relevant to the school health program (others used the space to vent feelings about the school, the teachers or the questionnaire itself). The comments were 17.8% favourable and 82.2% negative or suggesting improvements. As shown in Table 23, no school had more favourable comments than negative ones. Virtually all of the favourable comments ($^{15}/_{18}$) came from parents of children in special education, and more than half of these ($^{8}/_{15}$) came from school no. 2, the large English language school for EMR children. The positive comments were generally just expressions of satisfaction with health services, often relating to a particular experience with an individual nurse, although there were a few comments expressing satisfaction with hearing and vision screening programs and health education programs and teaching of personal hygiene.

Of the 83 negative comments, a relatively high proportion came from parents of children in regular classes (37.3%). Lack of

health education programs and material was the most frequent negative comment (about half) in both groups, and this trend was more pronounced in the special education group. For this group of parents, personal hygiene was the most important topic which they felt should be taught, followed by nutrition, dental, sex and smoking in that order. For the parents of regular class pupils, nutrition was most important.

In the special education group, parents frequently commented that they would like more medical examinations or more detailed examinations performed on their children at school (12) and 2 parents even felt there should be doctors permanently based in the schools. There were 4 parents who did not want any health care given at school.

In the regular class group, 4 parents mentioned they would like to see more teaching regarding how to obtain and appropriately use health care services. This point was not suggested by any parents in the special education group.

In summary then, the comments reflect parental concern for health education, with priority on personal hygiene for special education students and nutrition education for all children. The comments were generally in favour of more medical and dental care in the schools, although some indicated unreasonable expectations for what this would accomplish (e.g. resolution of learning problems). Some of the comments also reflected ignorance of the health care system as it exists. For example, one mother of a 12 year old asked for free

dental care in the schools because dental care is too costly, when in fact dental care for 12 year olds was covered by universal health insurance at the time of the survey, indicating that this mother's dissatisfaction could have been allayed by the school health service informing her, and linking her with a dentist in the community who would provide the needed service.

IV. 1/ Comparison of School Records with Survey Results

In one school (no. 4) a comparison of the school health records with the questionnaire results was undertaken both as a minimal sort of validation of the questionnaire results, and to get a feeling for the school health records. As previously mentioned, only $^{51}/_{162}$ children surveyed had charts which could reasonably be compared with the results of this survey. 44 of these 51 questionnaires were available. Comparisons were made on the responses to questions 1(a), 6(a), 8, 9, and 12. (Appendix A through D), that is, the questions asking about primary care physician, medical conditions, medication use, wearing of glasses and whether the child had a dentist.

In 35 of these charts no additional information was obtained from review of school health charts. In 4 cases, the school health charts confirmed that information which was left blank by the parents on our questionnaire was also missing in the school chart. In only 4 cases did the school health chart provide additional information not present in the questionnaire. The breakdown of this information is as follows: 1 case of a medical condition known at school; the name of a hospital used as a primary care source by one child; and the name of a doctor for two children in whom none had been named - however in both cases this was the DSC consultant pediatrician who had examined a few children at school.

SECTION V

DISCUSSION

V Discussion

V. 1 Gaps in Medical Care

This study has examined the health problems and health care of adolescents in special classes for the mentally retarded, classes for slow learners and learning disabled, and normal classes through the mechanism of parent responses to a questionnaire. It appears that there are some gaps between what the literature suggests is needed by these children, and what they are actually receiving.

Primary and specialist level care are clearly inadequate for this population. Nearly half in each group have no relationship with a primary care physician, and reference to Table 17shows that even in the case of retarded children with an additional chronic disease, nearly one fifth do not have a relationship with either a primary care source or a specialist. It could be argued that all retarded children should have both. The same table shows that having a specialist is highly related to being known to have an additional handicapping condition. It is impossible to say whether it indicates simply that those who are fortunate or persistent enough to have their chronic condition diagnosed eventually get to a specialist, or whether it indicates that those with chronic conditions get better specialist care. As we shall see later, there is a rather low prevalence of some types of chronic conditions in the population served, compared to what is expected from the literature.

The same table may be used to lend support to the findings of Pless et al[32] in the Rochester health studies, that when a specialist begins to take care of one condition in the child, the primary care physician loses his role. The bottom row of this table shows the very small proportion of the children who have both a specialist and a primary care physician.

Emergency and after hours care for a febrile illness is likely to be obtained at a hospital emergency department and most commonly a general hospital as opposed to a pediatric institution.

Medication use is similar in the three groups, and involves mostly over the counter drugs such as antihistamines and decongestants. Perhaps the most surprising finding is the very small number of children on stimulant medication (only 5 in the entire study). Considering the controversy surrounding the use of these medications[47] this is perhaps a blessing. However, it almost certainly is an indicator of a lack of psychiatric and pediatric care in the children based on average practice patterns in North America.[54] Group II is the group which should contain the largest number of hyperactive children and about one third of these children are likely to fall into that category.

In some speciality areas, children are receiving care which nearly corresponds with literature estimates of their needs.

Neurology, for example, seems to be close to the expected. 10% of retarded children and 5.6% of special education children are followed by a neurologist. The prevalence of epilepsy in the retarded group (6.2%) corresponds with the expected value of 6% in Table 8 . Cerebral palsy at 2.2% in the retarded is perhaps a little low but not out of keeping with literature estimates of about 4%. The literature would suggest however, that at least 26% of mildly retarded children have a neurological diagnosis of some sort, so there may be under-service in this area.

Orthopedic specialists were following 5.7% of the mildly retarded group studied. There are no figures available to suggest whether this meets the needs or not.

The same proportion of each group wear glasses, although clinical studies suggest that the need for ophthalmological care in the retarded and boderline retarded is about twice the normal. Ophthalmologists were seldom mentioned as medical specialists seen by their children.

Otolaryngologists were seen by less than 2% of the entire population. This is almost certainly underutilization at least for the retarded, of whom at least 4% would be expected to have significant hearing loss.

The biggest area of inadequate service utilization is clearly in the field of psychiatry and its related disciplines. Approximately

40% of both handicapped groups could be expected to have behavioural problems. Reference to Table 15 shows that 50% of the retarded and 40% of the educationally backward group had behaviour symptoms reported by their parents, while this was the case for only 22% of the control group. Annecdotal experience talking to parents during the study suggests that this is a major area of concern. The biggest single area of concern of parents of severely retarded children (the school which did not participate) was the behaviour of their retarded adolescents. After addressing a meeting of the parents committee, the author was deluged with parents who had tragic stories about difficulty coping with the behaviour of their retarded adolescents, and the problems they had encountered in finding any help for these problems. The nurses report the same findings and 20% of the referrals made by school nurses to a new school health clinic at the Montreal Children's Hospital have been for behavioural problems. The vast majority of these children are in special classes or special schools.

Unfortunately, the survey questionnaire did not ask questions about services such as rehabilitation, physiotherapy, speech therapy, social work, and other disciplines. The 15% limited activity in the retarded, and 8.6% in the special class group, indicates that the needs for these services are likely great. With the exception of speech on a limited scale, none of these services are offered at

school, and there is a need to find out whether they are being received by those who need them. Not a single child was followed by an M.D. Rehabilitation specialist.

The need for social services for the retarded is beautifully described in a review by Adams[48] and includes counseling, child advocacy, and financial assistance. Good social service must interact with all the services offered to retarded children, and particularly must coordinate well with psychiatry and other behavioural services. Again, this study does not address this question directly. There is however, no coordinated social service effort for the handicapped in the area of DSC-M.G.H., and the main social service agency providing care in this area is known to be aware of this deficit and has a sub-committee examining it now.

In the area of dental care, ideally 100% of the children in each group should have seen a dentist in the past year. Reference to Table 21 shows that far fewer Group II children had seen a dentist than the controls (group III). Just over half the study population had seen a dentist in the past year, leaving a lot of room for improvement. It has been suggested[30] that there are both parental and provider barriers to dental care of retarded children. Whether educationally backward children have the same barriers (financial, fear of causing a fuss, and provider uncertainty in how to handle the child) is not known, but clearly this group of

educationally backward children were receiving less care than their normal counterparts in the same school (group III). The parental comment mentioned in section IV. 10 suggests that some parents are unaware that financial barriers to dental care of children have been removed in Quebec (now up to the age of 16). However, financial barriers alone do not likely explain the discrepancies in services found.

Both dental and primary care were highly related to social class in the study population. This finding is no surprise and has been documented often before. However, the fact that so few children in social classes IV and V have primary care physicians should be an incentive to the DSC to make the school health service more useful in schools serving populations from these poorer districts.

Finally, the fact that there is a biological gradient from groups I to III in the prevalence of most problems reported with the exception of allergy and asthma, suggests the possibility that all kinds of health care needs are greater than normal, both in the special classes as well as special schools.

V. 2 Some Limitations of the Study

There are some important problems with the study design and implementation which make generalizations from this study inappropriate. The sample selection is not a random one, and the division into categories of educational disability may vary with the school board involved. Children in the lower socioeconomic status (SES) areas of the DSC were of specific interest, and therefore the selection of schools was skewed towards the lower SES, and of course to schools which would agree to participate. The selection of controls from the three schools with special classes was random, and therefore should represent a fairly good match for group II at least, although the inclusion of school 4 in group II may make this less true.

The division of the children into 3 groups is an educational classification. Each school commission has its own definition of learning disabilities and they are not necessarily comparable. They are also not necessarily based strictly on IQ and therefore there is undoubtedly some overlap between groups. There are probably some mildly retarded children attending school no. 4, and conversely some borderline children probably attend school no. 2. School no. 5 has a few children with IQ's below 50 who should be classified as severe. Educational classification takes place without medical evaluation. For all of the above reasons there are differences in important demographic variables between the groups with regards

to age, sex, social class and language. These differences make it impossible to relate the findings to a particular population base. The social class bias is likely to be the most important one, and it is only because the retarded group has the highest social class that it is felt reasonable to compare the groups at all.

Since the goal of the study was to provide a data base for administrative divisions regarding school health programs, it may be fair to compare the groups.

Another factor which limits generalizations is the age of the children in this study. High schools were chosen because by that time ascertainment of educational problems is likely to be more complete than at the elementary school level. However, it is argued by some that by the mid-teens, mentally retarded children are "burned out cases" as far as the medical profession is concerned, and that there is nothing left to do for them. While it is difficult to accept this kind of argument, it has to be acknowledged that for a variety of reasons, adolescents are likely to receive less adequate medical care than younger children, and this may affect the reporting of relationships with various types of providers. The effect ought to be equal in all groups however, and if anything, retarded children ought to maintain better contact with good medical facilities. There is some evidence [32] that parents of retarded and other handicapped children experience great frustration and disappointment with medical

care early in their child's life, and may be inclined to give up contact with medical professionals. However, for whatever reasons, educationally handicapped children have greater needs for health care and our data suggests that they do not have as good care in the fields of dentistry and behavioural service, that primary care is the same (and lacking) in all groups, and that while specialists are more commonly used by the educationally handicapped, there is a suggestion that in at least some areas they are not used to the expected degree of need.

There are also some problems with the survey methodology which may affect the results. The response rate was better from the handicapped groups, and the reasons were not investigated. One contributing factor was the fact that school no. 6, which contained more than a third of the normal controls, had a very poor response rate and did not receive a third mailing. However, this does not account for all of the poor response. There was no validation performed to ensure that non-responding controls were not different from responding controls. On the other hand, the excellent response from the two handicapped groups (78%) might be interpreted as indicating that these parents are especially interested in school health programs.

Finally, there is a problem with the question which asks about specialists, which was overlooked initially. Parents were

given only one space to write in the name of a specialist (although quite a few put in more than one), and the probe in the question reminds the parents that neurologists, orthopedic surgeons and urologists are medical specialists. The first two were the specialists who were expected to be used most frequently. However, a probe like that should always include other names such as psychiatrist and ophthalmologist, who are likely to be needed frequently, but who might not be regarded by some parents as medical specialists.

For all these reasons, interpretations of the data must be cautious and may not be generalizable beyond the high school population of the DSC Montreal General Hospital.

V. 3 Implications for the School Health Program and the DSC

In the process of carrying out this study, it became abundantly clear that there is a lack of coordination of services for the retarded and educationally handicapped in the population studied. Accordingly it would be short-sighted to discuss implications resulting from this study in relation to the school health program alone.

Mental retardation is an important handicapping condition affecting perhaps 3% of the population. It overlaps with many types of physical handicaps and therefore requires significant medical input, and a similar pattern of life-long service integration to that required by children with other types of handicap. Thus if any coordinating body is set up to deal with handicapped children, it should deal with all types of handicap. Whether children with learning disabilities and boderline intelligence should be included in a coordinating service is a matter for debate. The deleterious effects of labelling a child must be balanced against the real increase in needs which occurs for these children in the social, behavioural and educational and vocational areas, where coordinated service is hard to find. They may also have marginally increased traditional needs.

The model proposed by Brewer and Kakalik[44] of developing Regional Direction Centers for the coordination of the care of the handicapped is very attractive. The question arises though as to what system should be responsible for developing such a coordinating

center. The DSC with it's target population of 200,000 - 250,000 is a potential location. The social service agencies, which are divided along linguistic lines at present (French and English) would be another possible location. The English agency in Montreal serves 600,000 population on the Island of Montreal, and the French agency roughly 1.5 million. Other social service agencies outside major metropolitan areas serve smaller populations. The educational system would be another possibility, but it is clear that most children with significant retardation or physical handicap are diagnosed much earlier than school age, usually through the medical care system, and their needs for service begin early. It is the milder handicaps which are picked up at school. Another possible site would be a voluntary organization. However these organizations are usually concerned with one specific type of handicap, and therefore would have difficulty coordinating care for multiply handicapped children. The Bill on the handicapped, passed in 1980 created an Office of the Handicapped, a separate government body which is supposed to perform some coordinating role, but it is not clear how direct a role it will play. It has the authority now to examine programs for the handicapped and even to close down programs which do not meet requirements. However, its future role is not clear, and it will not likely coordinate personal services and maintain records as recommended by Brewer and Kakalik, at least in the near future. It may provide an

important advocacy service. The needs of the handicapped should at least be a priority at the Regional Council level (CRSSS) where medical and social services can be coordinated, and the DSC should examine its role in the care of handicapped children.

The school health system, which is run by the DSC's, should form a part of any system of care for the educationally handicapped. To expect that the School Health Service alone can be responsible for the health and welfare of these children would be unrealistic. It is clear that at least for the population studied, parents of children in special classes and lower SES schools would not be resistant to more involvement of the school health program in the care of their children. However, the program will remain ineffective if nurses can do nothing more than point out a problem to the parents in a letter.

It is clear that primary care of these children is poor and that services for behavioural problems are particularly underutilized. Dental care is inadequate.

It seems obvious that the school health system should become more of a coordinating agency for linking these children up with needed types of care. Nader et al[49] demonstrated that such a model could work in Rochester at similar cost to a traditional service. In this case the school health team (doctor and nurse) worked in conjunction with a Neighbourhood Health Center. In the case of the DSC in Montreal, there are no school physicians and

nurses seem to be completely isolated from medical care providers. The CLSC's by design would seem to be likely places to start linking primary care with school health services, but at present they provide only 10% of health services in Quebec, and the complete absence of specialists in these organizations is a drawback. With time these problems may improve. However in the meantime, it seems reasonable that the DSC should seek out and identify sources of primary medical and dental care which are interested and willing to care for educationally handicapped children (not all primary care physicians are). When specialist services are required

> ... it may be necessary to have a link between the school health system and speciality services such as those provided at university teaching hospitals. A possible model for this is the School Health Clinic which has since been started at the Montreal Children's Hospital, where specialist care for children from the schools is provided, and coordinated by a pediatrician who then communicates back to the school nurse, and eventually refers the child back to a primary care source in his neighbourhood.

Nader[50] identifies some of the barriers which exist in evolving this kind of care. He believes that lack of communication is the most common barrier, and this seems to be no exception in DSC-MGH. The nurses are isolated and do not have good communication with medical practitioners and sometimes not with teachers or

social workers either, because they are spread too thinly, or because natural barriers which exist between these various disciplines are too difficult to break down. Again, better communication is desirable, and the nurses must change their orientation so that they perceive of themselves as important coordinating health professionals. Silver[51] in a recent article supports a more intensive involvement in comprehensive health care for the School Health Service, and sees it as an integral part of a total health service to children. In the case of the handicapped children surveyed in this study, such an orientation seems desirable.

Other models of school health delivery which are being tested in the U.S under the auspices of the Robert Wood Johnson Foundation[52] are experimenting with total child health care delivery through the school for schoolchildren and their families. This model would not seem to be appropriate here at present when there is the possibility of linking children with existing services, and the financial barriers to care are removed through Universal Health Insurance.

It goes without saying that the school health records must be improved in order to implement any change in orientation.

VI Summary

Gaps in primary medical and dental care have been found in the entire population of high school students surveyed, and these are highly related to social class. In the retarded and special education groups there appears to be underutilization of other types of specialists, especially those in the behavioural field. Parents are not generally against more involvement with school health services. Consequently the school health service could be a more effective program if it re-oriented itself more towards comprehensive health services, and acted to link particularly the special education students with needed services, and to coordinate these services. The school health service could become part of a mechanism of comprehensive service delivery to all handicapped children, and Quebec with it's organized health and social service system has the necessary prerequisites for such a service to be implemented. The DSC's should advocate for such a service.

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ID# _____ APPENDIX H

The questions we are asking are about your son/daughter _____ _____ who is in a special class at _____.

DO NOT WRITE IN THIS COLUMN

1. Does your child have his/her own doctor who sees him/her for things like coughs, sore throats, and general check ups? ☐ 12

YES☐ NO☐

IF YES a) Dr's NAME _____

ADDRESS _____

b) About how many times did he see this doctor in the last year? _____ ☐ 13

c) Does this doctor also give vaccinations? ☐ 14

YES☐ NO☐

d) Does this doctor weigh and measure your child each year? ☐ 15

YES☐ NO☐

2. Does your child see any specialist doctor? (such as neurologist, orthopedic surgeon, urologist, etc.) ☐ 16

YES☐ NO☐

IF YES a) Dr's NAME _____ ☐ 17

ADDRESS _____ ☐ 18

b) Did your child see this specialist in the last year? ☐ 19

YES☐ NO☐ ☐ 20

3. If your child has more than one doctor, does one of his doctors keep track of everything that happens to him/her? ☐ 21

YES☐ NO☐

4. Does your child have any problem or difficulty with any of the following?:

i) His/her Behaviour	YES☐	NO☐	22	☐ 22 ☐ 23
ii) Control of temper	YES☐	NO☐	23	
iii) Dressing by himself	YES☐	NO☐	24	☐ 24 ☐ 25
iv) Eating by himself	YES☐	NO☐	25	
v) Getting around the house	YES☐	NO☐	26	☐ 26 ☐ 27
vi) Getting around the city	YES☐	NO☐	27	
vii) Going to the bathroom	YES☐	NO☐	28	☐ 28 ☐ 29
viii) Making friends	YES☐	NO☐	29	
ix) Running	YES☐	NO☐	30	☐ 30 ☐ 31
x) Sleeping	YES☐	NO☐	31	
xi) Walking	YES☐	NO☐	32	☐ 32 ☐ 33
xii) Washing	YES☐	NO☐	33	
xiii) Wetting the bed at night	YES☐	NO☐	34	☐ 34

5. Compared to other children his/her age, check the box which best describes you child's activity: ☐ 35

i) Confined to a wheel chair ☐
ii) Gets around, but can't play games, sports or gym ☐
iii) Can play all games and sports that other children do ☐

6. a) Does your child have any of the following medical conditions? ☐ 36

Asthma	YES☐	NO☐	☐ 37
Allergies	YES☐	NO☐	
Epilepsy or Convulsions	YES☐	NO☐	☐ 38
Heart disease	YES☐	NO☐	
Cerebral Palsy	YES☐	NO☐	☐ 39
Any deformity present at birth	YES☐	NO☐	

List any other medical problems your child has

_____

_____

_____

If you have answered YES to anything in part (a) or listed any other problems please answer parts (b) and (c).

b) Who do you go to mostly for treatment of these problems? ☐ 40

i) Your family doctor ☐
ii) Your pediatrician ☐
iii) A specialist ☐
iv) A local medical clinic ☐
(NAME _____)
v) The emergency department of a hospital ☐
(NAME _____)

c) Do you think any of these problems make your child's school work difficult? ☐ 41

YES☐ NO☐

7. If your child became very ill with cough and fever at night or on a weekend, where would you go to get treatment? ☐ 42

_____

8. Does your child take any medicines, pills, syrups or injections every day, or often for a few days at a time? ☐ 43

YES☐ NO☐

IF YES, please list the medicines

	NAME OF MEDICINE	WHAT IS IT FOR?	HOW OFTEN DOES HE TAKE IT?	
1				☐ 44
2				☐ 45
3				☐ 46

DO NOT WRITE IN THIS COLUMN

9. Does this child wear glasses? ☐ 47

YES☐ NO☐

10. Does this child wear a hearing aid? ☐ 48

YES☐ NO☐

11. Did this child have a general medical check up in the last two years? ☐ 49

YES☐ NO☐

12. Do you have a dentist who looks after your child's teeth? ☐ 50

YES☐ NO☐

If the answer is YES, did he see your child in the last year? ☐ 51

YES☐ NO☐

All the information you have given so far is about your child. We will keep it all confidential if you wish. However, the information would be useful to the school nurse or doctor, and if you would like we will transfer questions 1-12 to the school nurse if you check the right box below.

YES, I would like questions 1-12 to go to the school nurse ☐ ☐ 52

NO, I would like questions 1-12 to be destroyed ☐

Finally, we need a little information about you. This will all remain confidential, no matter what you answered above, and will be destroyed after the study is complete.

13. Is the person filling out this questionnaire the child's: ☐ 53

Mother ☐
Father ☐
Another family member ☐
A legal guardian ☐

14. How many years of school did the child's father finish? ☐☐ 55

15. How many years of school did the child's mother finish? ☐☐ 57

16. What is the occupation of the father? _____ ☐ 58
Is he presently employed?

YES☐ NO☐ DON'T KNOW☐

17. What is the occupation of the mother? _____ ☐ 59
Is she working outside the home now?

YES☐ NO☐ DON'T KNOW☐

18. Is the family supported by ☐ 60

WELFARE YES☐ NO☐
UNEMPLOYMENT INSURANCE YES☐ NO☐

IF YES, do you find that the money provided from welfare or unemployment insurance is enough to support your family? ☐ 61

YES☐ NO☐

19. Do you think that if school doctors and nurses and dentists were more involved in taking care of your child, his/her health would be better? ☐ 62

YES☐ NO☐ DON'T KNOW☐

20. Do you think your child is learning enough about how to take care of his/her own health at school? ☐ 63

YES☐ NO☐ DON'T KNOW☐

If you have any comments or suggestions about school health please feel free to write them in the space provided below. We will welcome your comments.

☐ 64

_____

_____

_____

_____

_____

_____

_____

_____

THANK YOU VERY MUCH FOR YOUR TIME AND COOPERATION.

APPENDIX B

ID#_____

Les questions qui suivent concernent votre fils/fille_____

inscrit dans une clase spéciale à l'école_____.

N'ECRIVEZ PAS DANS CETTE ESPACE

1. Votre enfant a-t-il son médecin qui le voit pour des problèmes de toux, mal de gorge ou pour des examens de routine? ☐12

OUI☐ NON☐

SI OUI

a) NOM DU MEDECIN_____

ADRESSE _____

b) Combien de fois ce médecin a-t-il été consulté depuis un an? ☐13

_____

c) Votre médecin donne-t-il aussi des vaccins? ☐14

OUI☐ NON☐

d) Votre médecin pèse-t-il et mesure-t-il votre enfant chaque année? ☐15

OUI☐ NON☐

2. Votre enfant voit-il un médecin spécialiste? (neurologue, orthopédiste, urologue, etc.) ☐16

OUI☐ NON☐

SI OUI

a) NOM DU MEDECIN SPECIALISTE_____ ☐17

ADRESSE_____ ☐18

b) Votre enfant a-t-il vu ce médecin spécialiste depuis un an? ☐19

OUI☐ NON☐ ☐20

3. Si votre enfant voit plusieurs médecins, l'un d'eux garde-t-il un dossier sur tout ce qui survient à votre enfant? ☐21

OUI☐ NON☐

4. Votre enfant a-t-il des problèmes ou des difficultés concernant ce qui suit?:

i) Son comportement	OUI☐	NON☐ 22	☐22☐23
ii) Le contrôle de son caractère	OUI☐	NON☐ 23	
iii) S'habiller seul	OUI☐	NON☐ 24	☐24☐25
iv) Manger seul	OUI☐	NON☐ 25	
v) Circuler seul dans la maison	OUI☐	NON☐ 26	☐26☐27
vi) Circuler seul en ville	OUI☐	NON☐ 27	
vii) Aller à la toilette	OUI☐	NON☐ 28	☐28☐29
viii) Se faire des amis	OUI☐	NON☐ 29	
ix) Courrir	OUI☐	NON☐ 30	☐30☐31
x) Dormir	OUI☐	NON☐ 31	
xi) Marcher	OUI☐	NON☐ 32	☐32☐33
xii) Se laver	OUI☐	NON☐ 33	
xiii) Mouiller son lit la nuit	OUI☐	NON☐ 34	☐34

5. En comparaison avec les autres enfants de son âge, cochez la case qui décrit le mieux le niveau d'activité de votre enfant: ☐35

i) Confiné à une chaise roulant ☐
ii) Peut circuler mais ne peut pas s'adonner aux jeux et aux sports ☐
iii) Peut pratiquer les mêmes jeux et sports que les autres enfants ☐

6.a) Votre enfant souffre-t-il d'un des problèmes médicaux suivants:

Asthme	OUI☐	NON☐	☐36
Allergies	OUI☐	NON☐	☐37
Epilepsie ou convulsions	OUI☐	NON☐	☐38
Maladie de coeur	OUI☐	NON☐	☐39
Paralysie cérébrale	OUI☐	NON☐	
Malformation congénitale	OUI☐	NON☐	
	OUI☐	NON☐	

Enumérez tout autre problème médical dont souffre votre enfant

_____

_____

_____

Si vous avez répondu OUI à l'un des choix dans la section (a) ou si vous avez énumeré un autre problème médical, veuillez S.V.P. répondre aux sections (b) et (c).

b) Pour le traitement de ces problèmes, consultez-vous ☐40

i) Votre médecin de famille ☐
ii) Votre pédiatre ☐
iii) Un spécialiste ☐
iv) Une clinique médicale de votre voisinage ☐

(NOM de la clinique_____)

v) Une clinique d'urgence d'un hôpital ☐

(NOM de l'hôpital_____)

c) Croyez-vous que l'un de ces problèmes nuit au travail scolaire de votre enfant? ☐41

OUI☐ NON☐

7. Si votre enfant tombait malade avec de la toux et da la fièvre durant la nuit ou la fin de semaine, où iriez-vous pour recevoir des soins? ☐42

8. Votre enfant prend-il des médicaments chaque jour ou périodiquement pour quelques jours à la fois? ☐43

OUI☐ NON☐

SI OUI, énumérez ces médicaments

	NOM DU MEDICAMENT	A QUOI SERT LE MEDICAMENT?	COMBIEN DE FOIS EN PREND-IL?
1			
2			
3			

N'ECRIVEZ PAS DANS CETTE ESPACE

☐44 ☐45 ☐46

9. Votre enfant porte-t-il des lunettes? ☐47

OUI☐ NON☐

10. Votre enfant porte-t-il un appareil auditif? ☐48

OUI☐ NON☐

11. Votre enfant a-t-il eu un examen médical complet depuis deux ans? ☐49

OUI☐ NON☐

12. Votre enfant a-t-il un dentiste? ☐50

OUI☐ NON☐

SI OUI, ce dentiste a-t-il vu votre enfant depuis un an? ☐51

OUI☐ NON☐

Tous les renseignements que vous avez donné jusqu'à maintenant concernent votre enfant. Nous les garderons confidentiels si vous le désirez. Cependant, ces renseignements seraient très utiles à l'infirmière ou au médecin de l'école. Avec votre permission, nous communiquerons vos réponses aux questions 1-12 à l'infirmière scolaire, si vous cochez la case appropriée ci-dessous:

OUI, je désire que les réponses aux questions 1-12 soient remises à l'infirmière ☐

NON, je désire que les réponses aux questions 1-12 soient détruites ☐ ☐52

Pour compléter le questionnaire, nous aimerions avoir de renseignements sur vous-même. Ces renseignements demeuront confidentiels et cette partie du questionnaire sera détruite l'étude terminée.

13. La personne qui répond à ce questionnaire est-elle: ☐53

La mère de l'enfant ☐
Le père de l'enfant ☐
Un autre membre de la famille ☐
Le tuteur légal ☐

14. Combien d'années de scolarité le père de l'enfant a-t-il complétées? _____ ☐☐55

15. Combien d'années de scolarité la mère de l'enfant a-t-elle complétées? _____ ☐☐57

16. Quelle est l'occupation du père?_____ ☐58
Occupe-t-il présentement un emploi?

OUI☐ NON☐ NE SAIT PAS☐

17. Quelle est l'occupation de la mère?_____ ☐59

Travaille-t-elle présentement à l'extérieur du foyer?

OUI☐ NON☐ NE SAIT PAS☐

18. La famille reçoit-elle une aide pécuniaire ☐60

du bien-être social OUI☐ NON☐

de l'assurance-chômage OUI☐ NON☐

SI OUI, trouvez-vous que le montant que vous recevez du bien-être social ou de l'assurance chômage est suffisant pour faire vivre votre famille? ☐61

OUI☐ NON☐

19. Croyez-vous que si les médecins, les infirmières et les dentistes à l'école étaient plus impliqués dans les soins de votre enfant, sa santé serait meilleure? ☐62

OUI☐ NON☐ NE SAIT PAS☐

20. Croyez-vous que votre enfant apprend suffisamment à prendre soin de sa propre santé à l'école? ☐63

OUI☐ NON☐ NE SAIT PAS☐

Si vous avez des commentaires ou des suggestions à faire au sujet du programme de santé à l'école, S.V.P. écrivez-les dans l'espace ci-dessous. Vos commentaires seront le bienvenus.

_____ ☐64
_____
_____
_____
_____
_____
_____

MERCI DE VOTRE TEMPS ET COLLABORATION

APPENDIX C

ID#_____

NON SCRIVETE IN QUESTO SPAZIO

Le domande che noi vi domandiamo sono al riguardo di vostro/vostra figlio/figlia _____ che si trova in una classe speciale a_____.

1. Vostro/a figlio/a à ilsuo dottore in cui sifa visitare da questo dottore per cose come il mal di gola, tosse e esami medicale? ☐ 12

SI☐ NO☐

SE SI a) NOME DEL DOTTORE_____

INDIRIZZO_____

b) Quanto volte a visto questo dottore nel periodo dell'anno scorso? ☐ 13

_____

c) E questo dottore che gli fa vacciazione? ☐ 14

SI☐ NO☐

d) E questo dottore che pesa e mesura suo/a figlio/a ogni anno? ☐ 15

SI NO

2. Vostro/a figlio/a e sotto la cura di un specialista? (come per esempio un neurologo, ortopedico chirurgo, urologo ecc.ecc.) ☐ 16

SI☐ NO☐

SE SI a) NOME DEL DOTTORE_____ ☐ 17

INDIRIZZO_____ ☐ 18

b) Suo/a figlio/a a visto questo specialista nel periodo del'anno scorso? ☐ 19

SI☐ NO☐ ☐ 20

☐ 21

3. Se suo/a figlio/a si fa visitare da piu di un dottore, almeno uno di questi dottore prende nota di tutto quello che succede a suo/a figlio/a?

SI☐ NO☐

4. Suo/a figlio/a à dei problemi oppure della difficoltà con qualcuno delle seguenti?

i) suo comportamiento	SI☐	NO☐	22
ii) controllo di umore	SI☐	NO☐	23
iii) vestirsi da lui stesso/lei stessa	SI☐	NO☐	24
iv) mangiare da lui stesso/lei stessa	SI☐	NO☐	25
v) camminare ingiro la-casa da solo/a	SI☐	NO☐	26
vi) andare ingiro la citta da solo/a	SI☐	NO☐	27
vii) andare al gabinetto da solo/a	SI☐	NO☐	28
viii) fare della amicia	SI☐	NO☐	29
ix) correre	SI☐	NO☐	30
x) dormire	SI☐	NO☐	31
xi) camminare	SI☐	NO☐	32
xii) lavarsi	SI☐	NO☐	33
xiii) bagnare il letto	SI☐	NO☐	34

☐ 22 ☐ 23
☐ 24 ☐ 25
☐ 26 ☐ 27
☐ 28 ☐ 29
☐ 30 ☐ 31
☐ 32 ☐ 33
☐ 34

5. Comparare con altri bambini della sua età, risponde si o no quale descrive meglio l'activita di suo/a figlio/a: ☐ 35

i) ritirato alla sedina a ruote ☐
ii) cammina ma non puo giocare oppure fare della ginnastica nella palestra ☐
iii) puo giocare tutti i giocci e fare del sport comme tutti l'altri bambini ☐

6.a) Suo/a figlio/a a qualcuno dei seguenti condizione medicale? ☐ 36

Asma	SI☐	NO☐	☐ 37
Allergia	SI☐	NO☐	☐ 38
Epilepsia	SI☐	NO☐	☐ 39
Malattia di cuore	SI☐	NO☐	
Paralisi cerebrale	SI☐	NO☐	
Qualche deformita alla nascita	SI☐	NO☐	

Lista altri problemi medicale di suo/a figlio/a

_____

_____

_____

Se avete risposto si su qualunque di parte (a) o si avete listato altri problemi si prega di rispondere parte (b) e (c).

b) Dove andati per il trattamento di questi problemi? ☐ 40

i) Dal dottore di famiglia ☐
ii) Dal pediatrico ☐
iii) Da un specialista ☐
iv) Clinica medicale ☐

(NOME_____)

v) Dall'emergenzia di un'ospedale ☐

(NOME_____)

c) Pensate-voi che qualunque di questi problemi posa della difficolta sul lavora di scuola di vostro/a figlio/a? ☐ 41

SI☐ NO☐

7. Se suo/a figlio/a cade ammalato/a con la tosse e febre durante la notte oppure durante la fine di settimana, dove andreisti per il trattamento? ☐ 42

_____

NON SCRIVETE IN QUESTO SPAZIO

8. Suo/a figlio/a prende delle medicine, pillole, sciroppo o iniezione ogni giorno, oppure spesso per un pò di giorni ogni volta? ☐ 43

SI☐ NO☐

SE SI, si prega di listare le medicine

NOME DELLE MEDICINE	PER QUALE RAGIONE?	QUANTO VOLTE PRENDE LE MEDICINE?
1		
2		
3		

☐ 44 ☐ 45 ☐ 46

9. Suo/a figlio/a porta la lente? ☐ 47

SI☐ NO☐

10. Suo/a figlio/a porta un aiutto dell'udienza? ☐ 48

SI☐ NO☐

11. Suo/a figlio/a a ricevuto un esamine medicale nel periodo di due anni fa? ☐ 49

SI☐ NO☐

12. Avete un dentista che visita i denti di suo/a figlio/a? ☐ 50

SI☐ NO☐

SE SI, il dentista a visitato i denti di suo/a figlio/a nel periodo del'anno scorso? ☐ 51

SI☐ NO☐

Tutte l'informazione che voi ci avete dato sono al riguardo di suo/a figlio/a. Questa informazione e confidanziale quindi non sarà data a nessuno se voi volete. Però questa informazione sarà di utile all'infermiera della scuola e il dottore e se voi volete noitransferemo l'informazione delle domande 1-12 all'infermiera della scuola se voi ci date la permissione.

SE SI Vorrei che l'informazione delle domande 1-12 siano transferiti all'infermiera ☐ ☐ 52

SE NO Vorrei che l'informazione sia destrutta ☐

Conclusivamento abbiamo bisogno di qualche informazione al riguardo de lei. Tutto questa informazione restera confidenziale è sarà distrutto dopo che il studio sarà completato.

13. La persona che riempe questo questionario e ☐ 53

la madre ☐
il padre ☐
un'altro membro della famiglia ☐
guardiano legale ☐

14. Quanti anni di scuola ha terminato il padre del bambino/della bambina?__ _____ ☐ 54 ☐ 55

15. Quanti anni di scuola ha terminato la madre del bambino/della bambina?_____ ☐ 56 ☐ 57

16. Cosé l'occupazione del padre?_____ ☐ 58
Lavora al presente?

SI☐ NO☐ NON SO☐

17. Cosé l'occupazione della madre?_____ ☐ 59
Lavora fuiri di casa al presente?

SI☐ NO☐ NON SO☐

18. La famiglia e sostenuta ☐ 60

dal benessere sociale SI☐ NO☐
dal benessere di dissoccupazione SI☐ NO☐

SE SI, trova che i soldi che gli sono fornoti dal benessere sociale oppure dal benessere di dissoccupazione sono abbastanza a sostenere la famiglia? ☐ 61

SI☐ NO☐

19. Pensa lei che se i dottori, l'infermieri e i dentisti delle scuole prendessero più cura di suo/a figlio/a la loro salute sarebbe più buona? ☐ 62

SI☐ NO☐ NON SO☐

20. Pensa lei che suo/a figlio/a sta imparando abbastanza di come tenersi cura di lui/lei stesso/a a scuola? ☐ 63

SI☐ NO☐ NON SO☐

Se avete dei commenti e delle suggestione al riguardo la scuola e la salute del bambino/della bambina, si prega di usare il spazio di sotto. Vostri commenti sarrano molto aggradito da noi.

_____ ☐ 64
_____
_____
_____
_____
_____
_____

GRACIE TANTO DEL VOSTRO TEMPO E DELLA VOSTRA COOPERAZIONE.

APPENDIX D

ID#_____

NAO ESCREVER NESTE ESPACO

As preguntas que estames a fazer, saô sobre o seu filho/a_____,
quem está a tomar uma aula especiale em_____.

1. O seu filho/a tem um médico quem o/a vê para a tosse, dores de garganta, e examinaçôes gerais? ☐ 12

SIM☐ NAÔ☐

SE SIM

a) Nome do Médico_____

Direcçaô_____

b) Quantas vezes foi ver este médico durante o ano?_____ ☐ 13

_____

c) Este médico tambem dá vaccinaçôes? ☐ 14

SIM☐ NAÔ☐

d) Ele pesa e toma as medidas da su criança cada ano? ☐ 15

SIM☐ NAÔ☐

2. O seu filho/a vê algum especialista?(Por exemplo, um neurologista, ou um urinologista.) ☐ 16

SIM☐ NAÔ☐

SE SIM

a) Nome do Especialista_____ ☐ 17

Direcçaô_____ ☐ 18

b) O seu filho/a a tem visto este especialista durante o ano passado? ☐ 19

SIM☐ NAÔ☐ ☐ 20

3. Se o seu filho/a tem mais de um médico quem o/a trata, há pelo menos un médico quem toma a conta e sabe tudo o que se passa com o seu filho/a? ☐ 21

SIM☐ NAÔ☐

4. O seu filho/a a tem algumas dificuldades em fazendo o seguido? :

i) O seu comportamento	SIM☐	NAÔ☐	☐ 22
ii) Controle de o seu humor	SIM☐	NAÔ☐	☐ 23
iii) Vestindo-se	SIM☐	NAÔ☐	☐ 24
iv) Comêndo sózino	SIM☐	NAÔ☐	☐ 25
v) Dar volta pela casa	SIM☐	NAÔ☐	☐ 26
vi) Dar volta pela cidade	SIM☐	NAÔ☐	☐ 27
vii) Indo ao retrete	SIM☐	NAÔ☐	☐ 28
viii) Fazendo amigos	SIM☐	NAÔ☐	☐ 29
ix) Correndo	SIM☐	NAÔ☐	☐ 30
x) Dormindo	SIM☐	NAÔ☐	☐ 31
xi) Andando	SIM☐	NAÔ☐	☐ 32
xii) Lavando-se	SIM☐	NAÔ☐	☐ 33
xiii) Molhando-se na cama a noite	SIM☐	NAÔ☐	☐ 34

5. Comparado com outras crianças da sua/seu idade,marca em baixo aquilo que o/a descrêve melhor: ☐ 35

a) Usa cadeira de rodas	SIM☐	NAÔ☐
b) Naô pode jogar, fazer disportos, nem gymnástica	SIM☐	NAÔ☐
c) Pode jogar e fazer disportos como outra criança	SIM☐	NAÔ☐

6. O seu filho/a sifre de alugma das próximas problemas medicais? ☐ 36

Asma	SIM☐	NAÔ☐	☐ 37
Alergias	SIM☐	NAÔ☐	☐ 38
Epilêpsia ou espasmos	SIM☐	NAÔ☐	☐ 39
Doença do coraçaô	SIM☐	NAÔ☐	
Alguma deformidade desde o nascimiento	SIM☐	NAÔ☐	

Por favor de fazer uma lista de outras problemas medicias:

_____

_____

_____

Se voçê respondeu SIM na socçaô (a), ou fez uma lista de outras problemas, por favor de responder as secçoês (b) e (c).

b) A quem vai voçê para tratar destas problemas? ☐ 40

i) O médico de família ☐
ii) Um médico de crianças ☐
iii) Um especialista ☐
iv) Uma clínica local ☐

(NOME DA CLINICA_____)

v) A secçaô de urgêçia de um hospital ☐

(NOME DO HOSPITAL_____)

c) Pensa voçê que alguma destas problemas faz os trabalhos da escola de sue filho/a mais difícil? ☐ 41

SIM☐ NAÔ☐

7. Se o seu filho/a ficasse doente com a tosse ou fébre á noite num fim de semana, voçê o levava aonde para o tratamento? ☐ 42

_____

NAO ESCREVER NESTE ESPACO

8. O seu filho/a toma alguma medicaçâo xarope, compromido ou injecçâo cada dia, ou variaz vezes durante ums dias? ☐ 43

SIM ☐ NÂO ☐

SE SIM, por favor de fazer uma lista, diziendo quais sâo:

	NOME DE REMÉDIO	UTILIZADO PARA QUÉ	QUANTAS VEZES TOMA
1			
2			
3			

☐ 44 ☐ 45 ☐ 46

9. O seu filho/a usa óculos? ☐ 47

SIM ☐ NÂO ☐

10. O seu filho/a usa um apoyo-audiêçia? ☐ 48

SIM ☐ NÂO ☐

11. O seu filho/a tem uma revista medical durante os dois anos passados? ☐ 49

SIM ☐ NÂO ☐

12. Voçê tem um dentista quem trata dos dentes do seu filho/a? ☐ 50

SIM ☐ NÂO ☐

SE SIM, ele tem visto a sua criança durante o ano passado? ☐ 51

SIM ☐ NÂO ☐

Toda a informaçâo que voçê nos tem dado é sobre o seu filho ou filha. Se voçê prefère, isto pode ficar confidênçiale. Contudo, esta informaçâo pederà ser útil à infermeira ou ao médico da escola. Se quiser nós podemos fazer um tranféro das preguntas 1-12 a infermeira da escola. Por favor de marcar em baixo a voça preferência:

SIM, quero que tranfère as preguntas 1 - 12 a infermeira ☐
NÂO, quero que as preguntas 1 - 12 sejam destroidas ☐ ☐ 52

Finalmente precisamos alguma informaçâo sobre voçê. Esta parte vai ser complétamente confidênciale, e vai ser destroído depois de o estudo estar completo.

13. A pessoa quem està a responder estas preguntas é (em relaçâo a esta criança): ☐ 53

A sua maê ☐
O seu pai ☐
Outro membro da família ☐
Guardiaô legal ☐

14. O pai da crianca estudou até que ano? _____ ☐ ☐ 55

15. A maê da criança estudou até que ano? _____ ☐ ☐ 57

16. O qué que é o trabalho do pai da criança? _____ ☐ 58
Ele està empregado neste momento?

SIM ☐ NÂO ☐ NÂO SEI ☐

17. O qué que é o trabalho da maê da criança? _____ ☐ 59
Ela està neste momento a trabalhando fora da casa?

SIM ☐ NÂO ☐ NÂO SEI ☐

18. A família està sustentado por:

O Bem-Estar	SIM ☐	NÂO ☐
Seguro de Desemprego	SIM ☐	NÂO ☐

☐ 60

SE SIM, acha voçê que o dinero fornecido da segurança de desemprego ou Bem-Estar é suficiente para sustentar a vossa família? ☐ 61

SIM ☐ NÂO ☐

19. Se os infermeiros, médicos ou dentistas da escola fossem mais comprometidos ao trabalho deles, acha que a saúde da sua criança seria melhor? ☐ 62

SIM ☐ NÂO ☐ NÂO SEI ☐

20. Acha que a sua criança està a aprender na escola suficiente como tratar-se do seu saúde? ☐ 63

SIM ☐ NÂO ☐ NÂO SEI ☐

Se voçê tem algumas sugestôes sobre a saúde na escola, por favor de se sentir libre e o escrever em baixo no espaço forneçido. As suas sugestôes vaô ser bem-vindas com muito prazer. ☐ 64

_____
_____
_____
_____
_____
_____
_____

AGRADECEMOS A VOSSA COOPERAÇÂO E DE TER TOMADO SEU TEMPO.

APPENDIX E

The Montreal Children's Hospital

A McGILL UNIVERSITY TEACHING HOSPITAL

Dear Parents,

the Department of Community Pediatrics at McGill University is conducting a study with the approval of your school, to find out what type of medical problems children in special education classes have, and how they obtain medical care. We hope the results will help us to plan a better school health service for all children in Montreal, especially those in special classes.

Please take 10 - 15 minutes to answer the questionnaire. Most questions require a simple check mark in the appropriate box. Return the questionnaire to your school nurse in the enclosed envelope.

This questionnaire is available in the following languages:

French
English
Italian
Portuguese

If you would prefer the questionnaire in one of these languages, or if you need assistance in answering some of these questions, please call 937-8511, ext. 243 during regular working hours.

Thank you for participating.

Yours Sincerely

M.E.K. Moffatt, M.D., FRCP

APPENDIX F

Children in normal classes have been selected from the school list by a scientific method, to provide a comparison for the children in special classes.

The Montreal Children's Hospital

A McGILL UNIVERSITY TEACHING HOSPITAL

Dear Parents,

the Department of Community Pediatrics at McGill University is conducting a study with the approval of your school, to find out what type of medical problems children in special education classes have, and how they obtain medical care. We hope the results will help us to plan a better school health service for all children in Montreal, especially those in special classes.

Please take 10 - 15 minutes to answer the questionnaire. Most questions require a simple check mark in the appropriate box. Return the questionnaire to ~~your school nurse~~ us in the enclosed envelope.

This questionnaire is available in the following languages:

French
English
Italian
Portuguese

If you would prefer the questionnaire in one of these languages, or if you need assistance in answering some of these questions, please call 937-8511, ext. 243 during regular working hours.

Thank you for participating.

Yours Sincerely

M.E.K. Moffatt, M.D., FRCP

Questionnaires in English and Italian included. Please answer only the most appropriate one.

APPENDIX G

The Montreal Children's Hospital

A McGILL UNIVERSITY TEACHING HOSPITAL

Dear Parents:

About three weeks ago we sent you a Health Survey questionnaire, and to date we have not heard from you.

School Health Services at your school are provided by the Department of Community Health of the Montreal General Hospital. We are doing the survey at their request, because information is badly needed concerning the types of health problems which students have, and the manner in which they get health care. The results of the survey will be used in the planning of school health services of the future.

We can assure complete confidentiality of all the results, and the questionnaire will be destroyed after the survey is over, unless you indicate otherwise by checking the YES box after question 12.

We are counting on your help, and hoping that you will take 10-15 minutes to answer the questionnaire and return it to us. The survey is supported by your school. If you would prefer to have the questionnaire in French, Italian or Portuguese please call 937-8511 loc. 243 during business hours.

Yours Sincerely

M.E.K. Moffatt, M.D. FRCP (c)

P.S. If you have already returned the questionnaire please accept our apologies and disregard this reminder.

APPENDIX H

Coding Sheet for School Health Survey

Column No.	
1 - 4	Identification number
5 - 6	Age in years
7	Sex male 1 female 2
8	School where student goes 1 Emile Nelligan 2 John Grant 3 Marymount 4 Esthere Blondin 5 St. Columban 6 St. Henri 9 Unknown
9	Language of Response 1 French (blue) 2 English (green) 3 Italian (yellow) 4 Portuguese (pink)
10	Blank
11	Study Status 1 special education 2 normal class 9 unknown
12	Doctor 1 yes - if Doctor named 2 no 9 missing data 3 an institution named as source of care

Column No.

13 How many times a year did he see doctor?

record actual number up to 7
7 7 or more
9 no answer or unknown
8 several times, but number unspecified

14 Vaccinations
1 yes
2 no
9 no response or unknown

15 Weigh or measure
1 yes
2 no
9 no response or unknown

16 Specialist(s)
1 yes
2 no
9 no answer or unknown

17, 18, 19 Types of specialists recorded
1 neurologist
2 pediatrician
3 orthopedist
4 general surgery
5 psychiatrist
6 other
7 otolaryngology
9 not applicable

20 Did he see specialist last year?
1 yes
2 no
9 no answer/not applicable

21 Is there one doctor who keeps track?
1 yes
2 no
9 no response (will assume this means no)

Column No.

Columns 22-34 refer to problems with:

22
23
24
25
26
27
28
29
30
31
32
33
34

1 yes
2 no
3 no answer

If coding difficult or does not make sense leave blank and consult.

35 Level of activity
- 1 wheel chair
- 2 restricted sports
- 3 normal
- 9 no answer

36 Any medical conditions?
- 1 yes
- 2 no
- 9 no answer

37, 38, 39 List of first 3 conditions named
- 1 Asthma
- 2 Allergies
- 3 Epilepsy
- 4 Heart disease/hypertension
- 5 Cerebral palsy
- 6 Birth defect
- 7 Skin problem
- 8 Other
- 9 Not applicable
- 0 Learning disability/psychiatric problem

Column No.

40 Place where the above problems are treated
- 1 family doctor
- 2 pediatrician
- 3 specialist
- 4 local medical clinic
- 5 emergency MCH
- 6 emergency Ste. Justine
- 7 emergency other or unspecified
- 9 not applicable

41 Whether health problems make school work harder
- 1 yes
- 2 no
- 9 not applicable

42 Emergency treatment for child at night
- 1 MCH
- 2 general hospital or unspecified hospital
- 3 a doctor's office
- 4 a CLSC
- 5 Hôpital Ste. Justine
- 6 self care
- 7 telemedique
- 9 no response

43 Does child take any medication?
- 1 yes
- 2 no
- 9 no response

44, 45, 46 Types of medications taken
- 1 Antihistamines
- 2 Theophylline preparations & other asthma remedies
- 3 Tranquilizers
- 4 CNS stimulants
- 5 Antibiotics/antituberculous drugs
- 6 Insulin or other hormones
- 7 Anticonvulsants
- 8 Other
- 9 Not applicable

Column No.

47 Wears glasses
- 1 yes
- 2 no
- 9 no response

48 Wears hearing aid
- 1 yes
- 2 no
- 9 no response

49 General medical check up in last 2 years
- 1 yes
- 2 no
- 9 no response

50 Dentist
- 1 yes
- 2 no
- 9 no response

51 Did he see dentist in last 2 years
- 1 yes
- 2 no
- 9 no response

52 Transfer to school file
- 1 yes
- 2 no (& no response)

53 Respondant is
- 1 mother
- 2 father
- 3 another family member
- 4 legal guardian

54, 55 Years of school of mother (Actual No.)

56, 57 Years of school of father (Actual No.)

Column No.

58 Family Status
- 1 Single Parent
- 2 Two Parent
- 3 Institution
- 9 Undetermined

59 Blank

60 Social Class of Family by Hollingshead
(leave blank for now - to be filled in by one trained coder for all questionnaires).

61 Financial Status: Perception of Needs - coded from responses to question 18.
- 1 No financial aid
- 2 Welfare - not enough
- 3 Welfare - sufficient
- 4 Unemployment - not enough
- 5 Unemployment - enough
- 6 Welfare - no answer about enough
- 7 Unemployment - no answer about enough
- 9 Not applicable or no answer

62 Whether doctors - nurses more involved would make child healthier
- 1 Yes
- 2 No
- 3 Don't know
- 9 No response

63 Question 20
Is Child learning enough about his own health?
- 1 Yes
- 2 No
- 3 Don't know

64 Commentaries made in open space
- 2 None
- 3 Positive comments about school health program
- 4 Criticism of school health progra
- 5 Criticism basically of the questionnaire
- 6 General complaint about school or teachers
- 7 Other