SURVEY OF MEDICAL, DENTAL AND NURSING SERVICES IN CENTRES FOR INTELLECTUALLY AND PHYSICALLY DISABLED CHILDREN IN CAPE TOWN AND ITS ENVIRONS

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DECLARATION

I, ANTHONY THOMAS READ WESTWOOD HEREBY DECLARE THAT THE WORK ON WHICH THIS THESIS IS BASED IS ORIGINAL (EXCEPT WHERE ACKNOWLEDGEMENTS INDICATE OTHERWISE) AND THAT NEITHER THE WHOLE WORK NOR ANY PART OF IT HAS BEEN, IS BEING, OR IS TO BE SUBMITTED FOR ANOTHER DEGREE AT THIS OR ANY OTHER UNIVERSITY.

I EMPOWER THE UNIVERSITY TO REPRODUCE FOR THE PURPOSE OF RESEARCH EITHER THE WHOLE OR ANY PORTION OF THE CONTENTS IN ANY MANNER WHATSOEVER.

1 September, 1992

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SUMMARY

This study describes the present medical, dental and nursing services in and used by centres for intellectually and physically impaired children in Cape Town and its environs. The information was gained by means of a structured questionnaire.

Thirty three of the 34 centres with a total of 3480 children are included. Twelve are Special Care Centres, 15 Training Centres and 6 are Special Schools. The number of children enrolled ranges from 9 to 400. At the time of the study 9 of the centres were for white children, 17 for coloured children, 5 for black children and 2 were multiracial.

Nine of the 11 Special Care Centres were not government supported while only 6 of the other centres were mainly funded from non-government sources.

Nurses employed at the centres had worked an average of 8 years at their centres, 23,5% of them having worked with disabled children prior to taking up their present posts. Of the Special Care Centres, only the two residential ones had a nurse on the staff. All the Special Schools had at least one nurse.

57,5% of the centres have a doctor or doctors visiting the centre. Two of the others have regular medical care for the children arranged with local health centres. All the Special Schools are visited while 25% of the Special Care Centres and 33% of the Training Centres receive medical visits. The number of doctors visiting a centre varies from 1 to 7. The doctors come from a variety of services both private and public. Most of the doctors do not receive remuneration for their services.

Of the 17 centres who have no doctors visiting, the majority depend on parents to take their children to a medical facility if there are problems related to the child's disability. For 7 of them, there is no other option.

A similar pattern exists for medical problems unrelated to the child's disability. Six centres make use of medical facilities as a first option in these circumstances.

For emergencies only 1 centre can count on a doctor to come to the centre. Ten centres may be able to get a doctor to come. The General Hospitals are the most common facility used in an emergency.

Dentists visit 4 of the centres. Twelve of the remaining 29 centres arrange regular dental visits for the children. Eleven of the 13 Special Care Centres do not have regular visits to a dentist arranged.

Fifteen centres receive visits from Community Nurses and these are local authority nurses in the main. Their functions are limited in all but one case to contraception, immunisation, Heaf testing or genetic services.

There are 10 centres which receive visits from neither doctor, dentist nor nurse (7 Special Care Centres, 3 Training Centres).

32% of the interviewees were satisfied with the services received. The most common improvement sought was to have a doctor visit the centre. Of those with a doctor visiting, 28% wanted the doctors to deal with intercurrent problems as well as the child's disability. The need for paramedical services was also expressed.

Further detail is presented and the implications of the findings discussed.

INTRODUCTORY NOTE

This study has been carried out at a time of momentous change in South Africa but also at a time when health and welfare services are in crisis. Many sweeping changes are likely, some introduced by legislation, others by the immense social and demographic shifts taking place. It is the hope of the author that in describing one aspect of the care of the disabled in the South Africa of 1991 a useful, if small, contribution may be made to divining a direction for services to children who have up to the present suffered the triple handicap of age, race and disability. The pre-eminent role of doctors in the care of the disabled has rightly been questioned and, in taking up the subject of the study, the author wishes to emphasise that he does not claim necessarily to be dealing with the most important and pressing concerns of the disabled and their families but is aiming to make a contribution consistent with his blinkered insight and circumscribed potential role.

Until very recently services to the disabled, as with other services in South Africa, were divided on racial lines. The terms "white", "coloured" and "black" are used in this document as dictated by the now-defunct Population Registration Act because this has had a significant impact on the delivery of services.

The reader will find herein a description of the study undertaken, its results and a discussion of the results in the light of local and international experience and perspectives on the health care of disabled children. The document ends with recommendations which the author considers appropriate to the present and, expecting enlightened vision from the new political dispensation in gestation, the future.

CHAPTER ONE

BACKGROUND AND MOTIVATION

Children with mental and physical disabilities are acknowledged to have special needs. Prominent among these are special health and educational requirements. These children are at risk of health problems related to their impairment such as epilepsy (O'Donohue 1985 p123-4, Corbett 1981, McKinley and Gordon 1986) and behaviour problems (Barker 1988 Chap.16, Rutter 1970), as well as having increased susceptibility to and morbidity from many childhood medical and dental diseases (Smith *et al* 1969, MacLaurin *et al* 1985, Wessels 1979, Jones 1988, Tesini 1981). They are also more prone to psychosocial maladjustment (Pless and Nolan, 1991). Thus the child with a disability may require more frequent (Nowachek, 1989) and often more specialised (Polnay and Hull, 1985 Chap. 14-16) care than most other children.

The complexity and range of problems experienced by children with physical and mental impairments and their families have militated against the development of effective and comprehensive services for them. (Ayers 1984, Kanthor 1974, Pless 1978, Pless 1976, Stein, Jessop and Reissman 1983). Added to these factors are sociopolitical restraining influences. The needs of people with disabilities are usually low in the priorities of a nation or society. This is aggravated in most underdeveloped countries. It is worsened in South Africa where ideology and legislation have prevented adequate services being developed for the majority of the disabled population.

Delivery of services to meet the special health and educational needs of children with disabilities has been approached in many ways and with varying degrees of success. In developed countries the approach used to be that of institutional care for most of the children. In the early 1970's, beginning in Scandinavia, the process of "normalization" began (Wolfensberger 1972). This has resulted in a "community" approach to the care of children with disabilities with the emphasis being on the child being cared for in the home with all necessary support systems in place in the commmunity. Ayers (1984) has shown how fallacious this concept can be unless very carefully instituted. He interviewed many mothers in their homes where they were caring for their very disabled children and found that they were not informed about the services available to them. Greenwood (1985) has described the changing concepts with time as having moved from "secularization" through "bureaucratization" and "medicalization" to "particularization". The last of these neologisms, our present state, is characterised by services being tailored to the individual's needs.

The educational outcome of this change is the attempt to have as many children with disabilities as possible educated with their "normal" peers, either in the same classroom or in special classes within the same school (Davies 1982 Chap. 7, Palfrey 1989). In the U.S.A. under Public Law 94-142 (PL 94-142), all children with disabilities have the right to appropriate education and the philosophy of the Act is the removal of barriers (including medical) between children with disabilities and their peers. Thus the children are to be in the "least restrictive" educational environment. The Warnock and Jay Reports in the late 1970s in the United Kingdom led to Education Acts which promote the entry of children with disabilities into regular educational environments (Polnay and Hull, 1985 Chap.16 & 17). However there remains a need for schools catering solely for children with disabilities (Lewis 1990, Davies 1982).

In South Africa most children with physical or intellectual disabilities who attend school attend those schools specially set up for their particular disability. This applies to the preschool age group as well although attempts to escape this mould such as the Peter Pan Preschool Centre in Cape Town are being made. This centre provides a setting for preschool children with and without disabilities to learn together (M. Ellis - personal communication). Apart from this project, integration has tended to happen by default. Cartwright *et al.* (1981), in a survey of learning problems in black primary school children on the East Rand, found that 8,7% of the children had a physical or mental handicap causing their learning difficulty. Disler *et al.* (1986a,b) found that many black children with locomotor disability were in mainstream classes owing to the lack of appropriate classes. This has also been the author's experience in recent years.

The broader needs of the children relating to health and rehabilitation are also addressed in various ways in different countries. In developed countries these facets of care have been dealt with mainly in an institution-based fashion with use of highly-trained professional staff. The main flaws in this approach have been the cost (to the client and the state), the urban predominance and poor communication between professionals and between staff and parents. Efforts to overcome these drawbacks are underway. In the United States of America adequate access for the disabled to health care is considered to be a Human Right and PL 94-142 was promulgated bringing effect to this. Under this law it is the duty of local education authorities to provide free services in the schools (special and ordinary) so that no child is denied the medical and ancillary care he or she needs to benefit to the maximum from his or her education. There are problems with implementation of this law owing to differing interpretations of the Act's provisions (eg. Palfrey, Singer *et al.*, 1985, Baird and Ashcroft, 1985) but the principle is established.

In the United Kingdom following the Court Report (1976), District Handicap Teams (now called Child Development Teams) were set up to see to the health and welfare needs of children with disabilities at home and at school (Committee on Child Health Services, 1976 pp225-232). These provide multidisciplinary evaluation and ongoing assessment and monitoring of care for children with disabilities in the area under their jurisdiction.

Systems of rehabilitation and training based in the home are available reducing the family's dependence on professionals and promoting optimum care for the children. An example of this is the Portage system first introduced in the U.S.A. (Shearer and Shearer 1976). With this system parents are given a programme of small training steps to assist their child's development in all areas. This is supervised in the home by a trained special educator. Systems which promote partnership between parent and professional are being introduced (Appleton and Minchom 1991, Mittler and McConachie 1984).

Underdeveloped countries tend to prefer what is called "Community Based Rehabilitation" which has the blessing of the World Health Organisation. This approach emphasises the role and resources of the family and local populace in caring for children with disabilities, reducing the reliance on highly trained specialists and sophisticated technology. Thorburn (1990) characterises the features of the past system for the care of disabled people that has led to this change of approach as:

- being in a few large cities and inaccessible to rural populations;
- having less than 3% of disabled people who need help receiving it;
- having most services for school-age children;
- requiring specialised staff and often not having it;
- high technology equipment and it often being in need of repair;
- very fragmented because it caters for specific disability categories separately without much sharing of resources, human or infrastructural.

Evaluation of this approach has not shown uniform success which has led to criticism by others who also do not subscribe to the institutional model (Miles 1990). The ability of families already under severe social stresses to cope with being the main channels of rehabilitation for their disabled child have been questioned (Jaffer and Jaffer, 1990).

How do these considerations of education, health and rehabilitation services relate to South Africa and where do the centres which are the focus of this study fit in? South Africa has in the past followed the Western institutional model modified by the inequality and discrimination inherent in apartheid. However provision of services for disabled people has been prioritised for white children.

Many centres have been set up to meet the special educational needs of physically and mentally impaired children. The Coordination Committee in the Year of the Disabled (1987) reported that there were 107 Training Centres for severely mentally retarded children of school age, 39 schools for children with cerebral palsy and 50 Special Care Centres in the Republic and the nominally independent homelands (Vol. 3, p9-10). These centres may provide preschool education, training in life skills or a normal educational curriculum. The centres also aim to cater for many of the other needs of the children and their families. The majority of these centres will offer day-care only but some have residential facilities.

For severely mentally and physically handicapped children for whom there are very limited training objectives, the Special Care Centres, either day-care or residential, offer the care and supervision they need.

The broad range of ages and the degree and type of impairment have led to a wide variety of centres being established. Added to this, a centre may have been set up by a state department, a non-governmental organisation, concerned local groups or parents of handicapped children. Thus they may range from small self-supporting groups with minimal facilities to large well-funded, well-equipped schools and training centres. This disparity has been compounded by the separation of the races under the policy of apartheid. For example, van der Westhuizen (1990) reports that, in the area of mental handicap, 62% of white children's needs are met compared to only 8% for blacks excluding the "homelands", and over half of the facilities in South Africa are for whites only. The Coordination Committee in 1987 estimated that facilities for white children catered for over 75% of the need as opposed to less than 20% for black children (Vol. 3, p9-10). Of a total of 7623 Training Centre places, 4106 were for white children and, of 5750 Special Care places, 3906 were so allocated. They stated that, for cerebral palsy, only in the Eastern Cape region was there a shortfall in educational places for white children (Vol. 14). In a study on the Witwatersrand, Cartwright *et al.* (1988), who had had difficulty placing mentally retarded children in facilities, estimated the 7,6% of black, 9,3% of coloured and 69,7% of white children's placement needs were met by existing facilities, and the services offered at the centres "varied widely". Eichhorn (1984), in a study in the Western Cape, showed that facilities for black and coloured mentally handicapped people were inadequate to meet existing and predicted needs. Disler *et al.* in studies in Bishop Lavis and Nyanga in 1986 (Disler *et al.*,1986a,b) showed that children with a locomotor disability are unlikely to be attending appropriate educational institutions.

In Cape Town approximately 3000 children are cared for in centres for the mentally and physically handicapped and the centres reflect the range and disparity already discussed.

As indicated in the first two paragraphs of this chapter, children with mental and physical disabilities often have many medical, dental, psychosocial and educational problems and thus require a comprehensive approach to management if their needs are to be met. Comprehensive care requires adequate attention to be given to primary, secondary and tertiary preventive health measures, to management of health problems, both physical and mental, and to social needs. This concept is discussed in detail in Section 6.1.

Little is known about how medical and dental care is delivered to children with disabilities in South Africa and most reports are local. Molteno (1990) describes an assessment and treatment centre based in a major institution. Here, developmental assessment is carried out by a multidisciplinary professional team with back-up from subspecialist doctors. All areas of the child's development and social background are examined and a plan established for ongoing management. Therapy of various kinds is offered but "the emphasis is always on parent instruction and home programmes" (p194). Surveys of care as an adjunct to prevalence studies have been carried out in Cape Town (Power 1977, Friedlander and Power 1982, Disler *et al.* 1986a,b).

In 1986, the Year of Disabled Persons, a co-ordinating committee was set up to report on services for disabled people in South Africa. In the Report, Disability in South Africa (Coordination Committee, 1987), the section on mental handicap makes no mention of medical care apart from at diagnosis. It is stated that

> "medical and paramedical staff make a great contribution to the successful upbringing and education of these pupils"

but no data is given. With respect to cerebral palsy, the Coordination Committee gives only in the most general terms a description of hospital services for children (Vol. 14, p28-29). In Vol. 11 of the report, in a discussion of treatment of people with physical disability, it is pointed out that all specialised services are in the main medical training centres. The expense of the private sector and the inadequate provision in provincial hospitals are highlighted (p23). Fragmentation is also accented as a major cause of poor coordination of health services for disabled people. Medical staff are seen as lacking knowledge of neurological disabilities. Recommendations include more hospital facilities amd community and travelling paramedical staff (p51). The role of doctors and dentists outside the hospital is not discussed except possibly by implication in the phrase: "effective follow-up mechanisms should be provided" (p51). Coordination of policy and service is seen as the responsibility of central government. The recommendations of this committee in these areas do not appear to have been implemented.

Attempts to provide care for children with disabilities in other ways have been made. Community-based rehabilitation services have been set up by the SACLA Health Project in Cape Town, for example, and a doctor from the Developmental Clinic at the Red Cross War Memorial Hospital sees children in a community setting at regular intervals obviating the need for attendance at the distant hospital (P. Lachman - personal communication). Similar care is given in some of the educational centres for children with disabilities but the medical and dental care given to children in the centres seems to be as disparate as the centres themselves. There are no statutory requirements regarding medical care in institutions for the disabled (Y. van der Westhuizen - personal communication) and there is no co-ordinated plan for Local Authorities or other health sectors to provide medical and dental care.

Many centres for children with disabilities have nurses on their staff. The nurse's role in the care of these children and coordination of the services (health-related and other) they receive can be critical (Dunn 1984, Crossland *et al.* 1986). Nurses from local health services are often responsible for the health care in institutions in their area and may provide immunisation, contraceptive advice and other preventive services. The range and comprehensiveness of these nursing services has not been documented in Cape Town or elsewhere in South Africa.

It would seem that, at present, for children at centres for the physically and mentally handicapped, access to a nurse, doctor or dentist appears often to be the result of history, personal contact and the proximity of hospitals and clinics.

It should be pointed out at the outset that the proportion of disabled persons receiving care and education in special centres in the Western Cape region is only about 48% of those who would benefit from these facilities and that this proportion varies considerably according to race (Grover *et al.*, 1987). Calculating the needs of the children from the estimated figures which Grover *et al.* give, only 1,4% of black children's needs are met as opposed to 45% for "coloured" children and 97% for whites. These 1984 figures are probably an overestimate of the present figure owing to the massive influx of black people to the Western Cape in recent years which will have overwhelmed the modest increase in places and the opening of most centres to all races. Thus any study of the health care of children in centres for the disabled will cover the health care available to relatively few of that population.

The purpose of this study is to examine how medical and dental opinions are obtained for children at the centres for the physically and mentally handicapped in Cape Town. With changing political and health structures this information could be useful in planning a co-ordinated and efficient service to children whose needs are ongoing, specialised and often enormous.

CHAPTER TWO

AIMS AND OBJECTIVES

AIM

To document the service given by doctors, dentists and nurses to children in centres for the physically and mentally impaired in Cape Town and environs in order that recommendations regarding this service may be made.

OBJECTIVES

To determine

1. the size and types of centre;
2. how many doctors and nurses see the children at the centres and how often;
3. how many centres are visited by dentists;
4. the organisational source of these health professionals;
5. which health facilities the centres use to obtain medical and dental help for the children;
6. how available such help is;
7. who pays the doctors and dentists involved;
8. the experience and qualifications of the nurses employed in the centres;
9. whether the centres are content with the health service for the children and what improvements they seek; and
10. to examine these findings in the light of the need for comprehensive care for the children in the centres; and
11. to make recommendations in this regard.

CHAPTER THREE

METHODOLOGY

3.1 DEFINITIONS

The terminology in the field of mental retardation is in a constant state of flux as professionals, families and the disabled themselves attempt to find words which are the least stigmatising. The most important area in which adequate distinction is sought is separating the concept of intellectual difficulty from mental illness as the social stigma attached to the latter is often transferred to the former. In using the term "intellectual impairment" in this study one must be aware that intellectual difficulties are but one aspect of the disability. Impaired scholastic and social functioning are also components of the concept of mental retardation (Clarke and Clarke 1986). As admission to most centres in South Africa is decided by I.Q. score, the intellectual component is the most appropriate to use in defining terms.

The terms "impairment", "disability" and "handicap" are used according to the definitions provided by the World Health Organisation (WHO, 1980):

Impairment - any loss or abnormality of psychological, physiological or anatomical structure of function.

Disability - any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being, resulting from an impairment.

Handicap - a disadvantage for a given individual, resulting from an impairment or disability, that prevents or limits the fulfilment of a role that is normal depending on age, sex, social and cultural factors for that individual.

Other terms used in the study are defined as follows:

Physical impairment - this includes children with neuromuscular impairments such as cerebral palsy or spina bifida. Visual and hearing impairments are not included.

Intellectual impairment - I.Q. <50 is generally used in Cape Town for admission to Training or Special Care centres. Centres for educable intellectually impaired children are not included.

Centre - a place established specifically for the care of physically and intellectually impaired children. This includes Special Care and Training Centres as well as schools but excludes hospitals.

Training Centre - caters for children under 18yrs of age with an I.Q. of 30-50. Children with associated physical impairment are admitted to some training centres.

Special Care Centre - caters for children with an I.Q. less than 30 and for those with secondary disabilities which render them unsuitable for admission to a training centre.

Special School caters for children with normal or borderline intelligence who because of their motor handicap cannot be accommodated at normal schools.

Day hospital - a community-based health centre with a curative service staffed partly by doctors. There are no inpatient beds and it is usually only open during the day.

Health facilities	-	Any health centre where doctors or dentists are available for consultation. This includes General Practitioners and District Surgeons.

3.2 STUDY DESIGN

The study is descriptive in design using a standard structured questionnaire.

3.3 STUDY POPULATION

All centres for children under the age of 18 years with physical and mental impairments in the Greater Cape Town area were included in the study. To ensure that the names of all centres were obtained the following authorities were contacted:

- the Child Care Information Centre of the Child Health Unit of the University of Cape Town;
- the coordinator of the Western Cape Forum for Mental Handicap;
- the head of the Cape Mental Health Society;
- the Cerebral Palsy Association, and
- the Society for the Physically Disabled.

The names and addresses of the 34 centres are shown in Appendix 3.

3.4 DATA COLLECTION

Four weeks prior to commencement of the study a letter (Appendix 4) was sent to the Principals of all the centres explaining the purpose of the study and requesting permission to interview the nurse or the Principal. This was followed by a telephone call to each of the centres by the researcher to confirm permission for the interview and to arrange a time for the interview with the interviewee.

3.4.1 Questionnaire

The questionnaire (Appendix 1) was drawn up by the researcher. The questionnaire was divided into 3 main sections:

- questions related to the centre and the interviewee;
- questions related to the nursing staff of the centre
- questions eliciting information on the doctors, dentists and community nurses and the cover given to the centres.

The questions aimed to cover Objectives 1 to 9 of the study so that Objectives 10 and 11 might be attained in an informed and realistic manner.

The questionnaire was only administered in English.

3.4.2 Population data

Information on the population group(s) served by the centres was obtained from the Directory of Services (Child Care Information Centre 1990) or, if the centre did not appear there, from the controlling body.

3.4.3 Interviewer

The researcher was the sole interviewer. A list of prompts and explanations for use during the interview was drawn up (Appendix 2). To ensure familiarity and facility with the questionnaire the interviewer administered it in a number of role-play situations with medical and lay persons for some of whom English was not the first language. A pilot study was also carried out (See below).

3.4.4 Interviewee

At each centre with a nurse on the staff the most senior nurse was the interviewee. At centres with no nurse on the staff, the principal or head was interviewed unless that person had a specific member of staff responsible for the children's health. The interviewee was encouraged to use Afrikaans or Xhosa if difficulties were experienced with English.

3.4.5 The interview

The interview was carried out at the centre during working hours. All interviews were to take place in the first 3 weeks of the fourth school term of 1991.

3.4.6 Pilot study

The questionnaire was piloted in 5 schools for the visually and hearing impaired in the same region as the main study. This provided the following information:

- the feasibility of the study
- the logistics of the study;
- any problems with data collection, and

enhanced experience with administering the questionnaire in the field.

3.4.7 Coding of data

This was carried out by the researcher at the time of the interview. The coding on the completed sheets was entered into a database based on the questionnaire using the Epiinfo computer-based epidemiology package (Center for Disease Control, Atlanta, 1987).

3.4.8 Analysis of data

This was done using the Epiinfo programme and interpretation of the results was undertaken by the researcher.

3.4.9 Ethics

The protocol for the study was approved by the Ethics and Research Committee of the University of Cape Town.

CHAPTER FOUR

RESULTS

SECTION 1

Number and Size of Centres

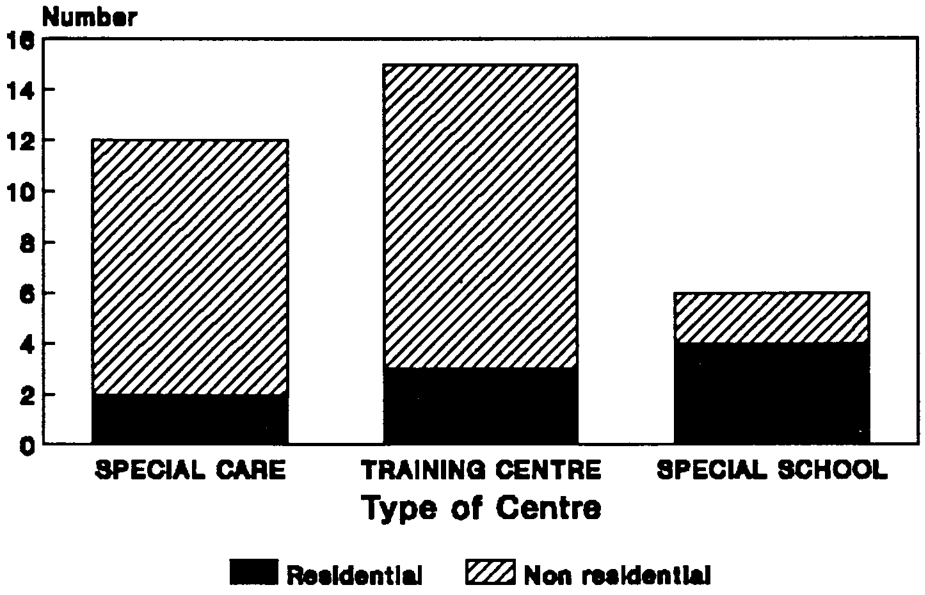
Thirty four centres were visited. At 33 of these the questionnaire was administered. Two appointments at one centre, a preschool Training Centre for intellectually impaired and normal children, were not kept by the interviewee. There are only 2 intellectually impaired children in this centre.

Seventeen centres have at least one nurse on the staff and in all cases the most senior nurse on the staff was interviewed. The supervisor or principal was interviewed in all other cases.

The number of centres by function is illustrated in Fig. 1 and the average number of children in the centres in Table 1.

FIGURE 1.

NUMBER AND TYPE OF CENTRE



Number = 33

It was found that all centres wwhich took children beyond primary school age had a number of young adults over 18 years of age still attending. The maximum age was 26 years. 2 of the Training Centres take only preschool children and one only primary school ages.

TABLE 1: NUMBER OF CHILDREN IN THE CENTRES

	Average	(Range)
Special School	252	(71 - 400)
Training College	86	(18 - 295)
Special Care	36	(9 - 90)

The smallest Special School with 71 pupils is the only one for black children and is less than half the size of the smallest of the other Special Schools.

Population Groups

Table 2 shows the centres by population group served.

TABLE 2: POPULATION GROUPS SERVED BY THE CENTRES

	Number of Centres (Number of Children)			
	White	Coloured	Black	Mixed
Special school	2 (660)	3 (756)	1 (71)	0
Training Centre	5 (670)	8 (760)	1 (107)	1 (48)
Special Care	2 (137)	6 (137)	3 (102)	1 (90)
TOTAL	**9 (1409)**	**17 (1653)**	**5 (280)**	**2 (138)**

Funding of the Centres

There was a marked difference in funding for the various centres. Table 3 shows the funding of the centres. When the Special Schools and the Special Care Centres are compared with the training centres using the Fisher Exact Test, the latter are significantly more likely to be state funded (p = 0,009 and 0,0128 respectively).

TABLE 3 FUNDING OF THE CENTRES

	Government Funded	Non-Government Funded
Special School	5	1
Training Centre	11	2
Special Care	2	11

The only Special School not to be funded in the main by the state is that for black children.

Interviewees

The interviewees had worked a mean of 6,6 years at their centres (Range 1-17 years).

SECTION 2

Nurses Employed at the Centres

The nurses interviewed had worked at their centre for from 3-17 years (Mean 8 years). All were State Registered Nurses and their other qualifications are shown in Table 4.

TABLE 4

NURSES' QUALIFICATIONS

DIPLOMA OR COURSE	
ORTHOPAEDIC NURSING	3
COMMUNITY NURSING	4
ADMINISTRATION	2
PAEDIATRIC PRIMARY CARE	1
BEHAVIOUR MODIFICATION	1
PSYCHIATRY	1
MIDWIFERY	8
CARDIOLOGY	1
MAJOR ABDOMINAL SURGERY	1

Four (23,5%) of these nurses had worked with disabled children prior to taking up their present posts. The average length of time was 8 years (Range 3-12 years).

At 4 centres there is more than 1 nurse employed. Two have 2 nurses, one has 3 and one residential Special Care Centre has 4 SRNs on the staff. All the additional nurses had gained their experience with disabled children in their present jobs. Length of service ranged from 2-11 years (Mean 6 years).

Analysis of nursing care by type of centre is shown in Table 5. The two Special Care Centres with nurses are the residential ones. Two of the 5 Training Centres for white children had a nurse as did 7 of the 8 for coloured children. The only Training Centre for black children and the two non-racial centres did not have a nurse. There is an average of 112 children per nurse in all centres for the physically and intellectually disabled.

TABLE 5: NUMBER OF NURSES IN THE CENTRES

	Number of Nurses			
	1	2	3	4
Special School	4	1	1	0
Training Centre	8	1	0	0
Special Care	1	0	0	1

All pupils in special schools have a nurse at the school. For 82% of children in Training Centres this is true and for Special Care Centres the figure is 23,3%. In special schools there are 167 children per nurse. In those Training Centres and Special Care Centres with nurses there are 128 and 17 pupils per nurse respectively. Analysis of this provision by race does not reach significance.

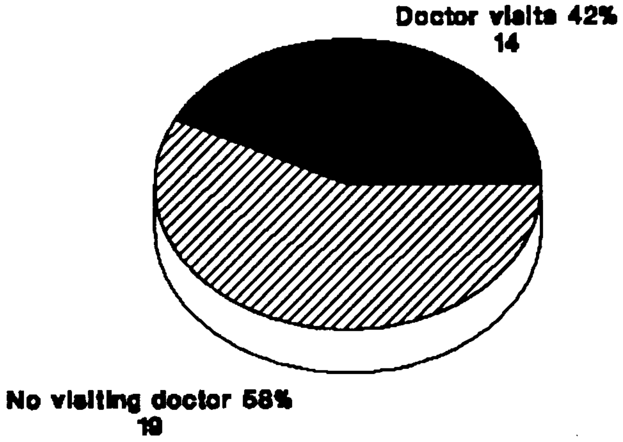
SECTION 3

QUESTION 1: Regular Visits by Doctors

As shown in Fig. 2, of the total of 33 centres visited, 19 (57,5%) do not have a doctor who comes to the centre although 2 of these have arrangements with local doctors for regular medical care for the children. One of these is a local General Practitioner who sees children from a residential Special Care Centre with 10 residents and the other is a Day Hospital at which children from a local Training Centre receive a biannual examination.

Figure 2

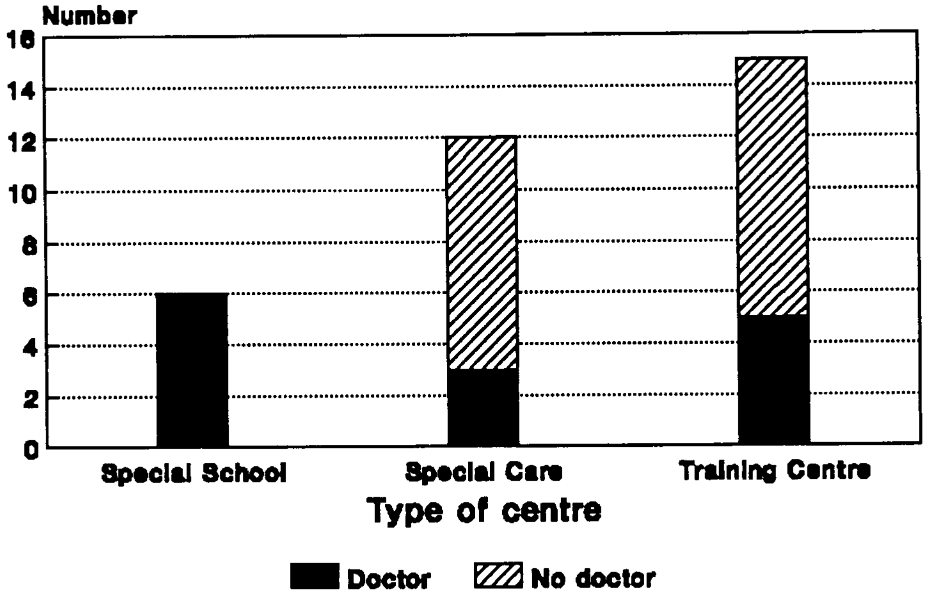
CENTRES WITH DOCTORS VISITING



N = 33

Fig. 3 shows those centres with a doctor visiting by type of centre. All Special Schools receive a visit from at least 3 doctors while 3(25%) out of 12 Special Care Centres receive a visit. Five (33,3%) out of the 15 Training Centres are visited. Three of these are for children who have physical as well as intellectual handicap.

FIGURE 3
DOCTORS VISITING BY TYPE OF SCHOOL



The number of doctors with involvement in the centres varies from 1 to 7 with the 3 Special Care Centres having 1 visiting doctor each.

How many and the speciality of the doctors is shown in Table 6.

TABLE 6: NUMBER OF VISITING DOCTORS

	NUMBER OF VISITING DOCTORS (Number of centres in brackets)					
	District Surgeon	GP	Spec Paed	Ortho-paedic	MO Other	Genetic
Special Care	1 ()	0 ()	1 ()	0 ()	1 ()	0 ()
Training Centre	0 ()	1 ()	2 () 3 ()	2 () 1 (3)	1 (3) 2 ()	1 (2)
Special School	0 ()	0 ()	1 (3) 2 (2)	3 (2) 2 ()	3 () 1 ()	1 (4)

"MO (other)" includes 2 psychiatrists and 2 doctors who take a special interest in cerebral palsy and visit a number of the Special Schools and Training Centres. One Special School receives a regular visit from an ENT surgeon who is based at a tertiary centre. No specialist neurologist, ophthalmologist or neurosurgeon renders a service at the centres on a regular basis.

There are 11 paediatricians who visit. Six of these are fulltime state employees and are based in tertiary centres. One is in fulltime private practice and 4 operate on a sessional basis in various health settings. All the orthopaedic surgeons have involvement in state hospitals. The 2 Geneticists are based in academic departments. The organisational source of the non-specialist medical officers was not clear or unknown.

How Often is a Doctor Present?

The majority (78,6%) of the 14 centres with visiting doctors has a doctor on the premises at least once a week. Two have a doctor every day and 3 two to four days per week. The Special School served by the fewest doctors has a visit every 3 months and at one of the 3 Special

Care centres the same frequency pertains. Although it has 7 doctors visiting, one Training Centre only has a doctor on the premises once a month.

Which Children are Seen?

Five (35,7%) of the centres ensure that the children are all seen by these doctors at least once a year. Two of these centres also use these doctors to obtain opinions on children who have problems between reviews. 2(14%) centres report that all children are seen at some time but not necessarily each year. Six (42%) centres use the doctors to see children with problems at the time of the visit and 4(28%) centres use them to see newly enrolled children. Three of these combine the 2 functions of the medical visit. One centre, a Special School, only uses the doctors to see newly enrolled children.

Neither the 2 centres which have a doctor on the premises every day nor the 2 with doctors 2-4 days per week use them to see children on a regular basis. Four centres with a weekly visit use the doctors for ensuring annual (or more frequent) reviews. All 4 centres are served by the same doctor.

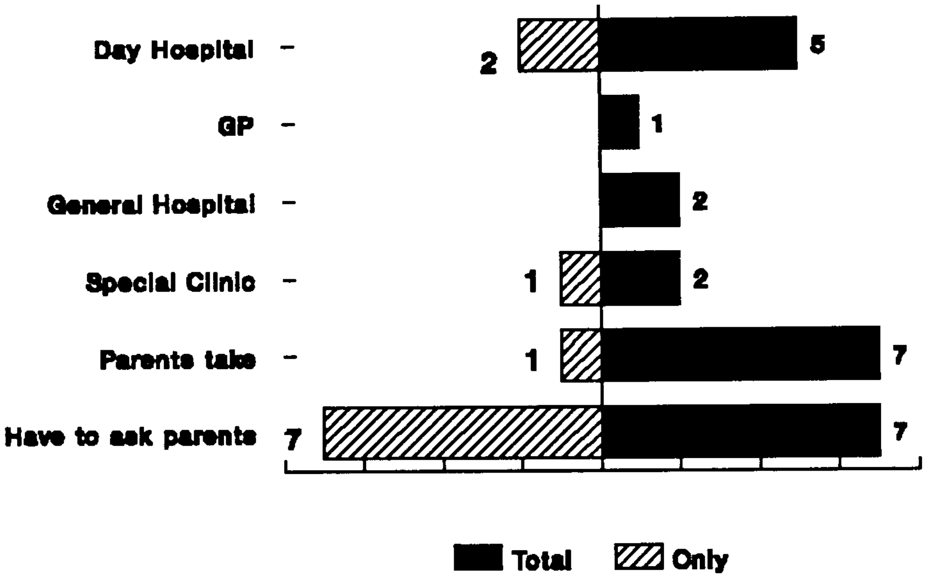
Who Pays the Doctors?

No visiting doctors are paid directly by any of the centres. For the majority (78,6%) of the centres doctors are paid by other authorities although the data did not indicate how many. Some of the doctors are paid by associations for the handicapped and others are salaried staff of state health departments who receive no extra payment for their visits although the proportions of each was not directly recorded. Three centres have doctors paid by their controlling body for visits undertaken and one centre's doctor is entirely unpaid for services rendered.

QUESTION 2: Centres with no Regular Doctor's Visits

There are 17 centres which have neither a visiting doctor nor regular reviews for the children under their care. If problems related to the child's impairment are encountered the referral pattern is as shown in Fig. 4.

FIGURE 4
REFERRAL OF RELATED PROBLEMS

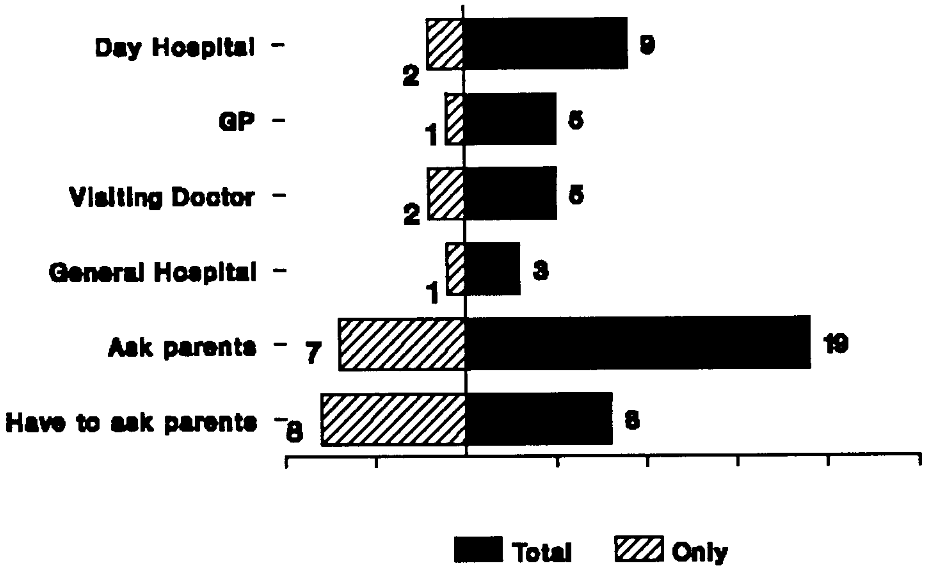


Six of the 7 centres which ask parents to take children to a doctor for these problems have other options if parents fail to meet their obligations (3 Day Hospital, 2 General Hospital, 1 Specialist clinic and GP). The use of a GP is one of 3 options open to one Training Centre. One centre was able to use a Specialist Neurology Clinic for all referrals of related problems.

QUESTION 3: Non-urgent Problems

For non-urgent unrelated medical problems the pattern of referral is shown in Fig 5.

FIGURE 5
REFERRAL OF UNRELATED PROBLEMS

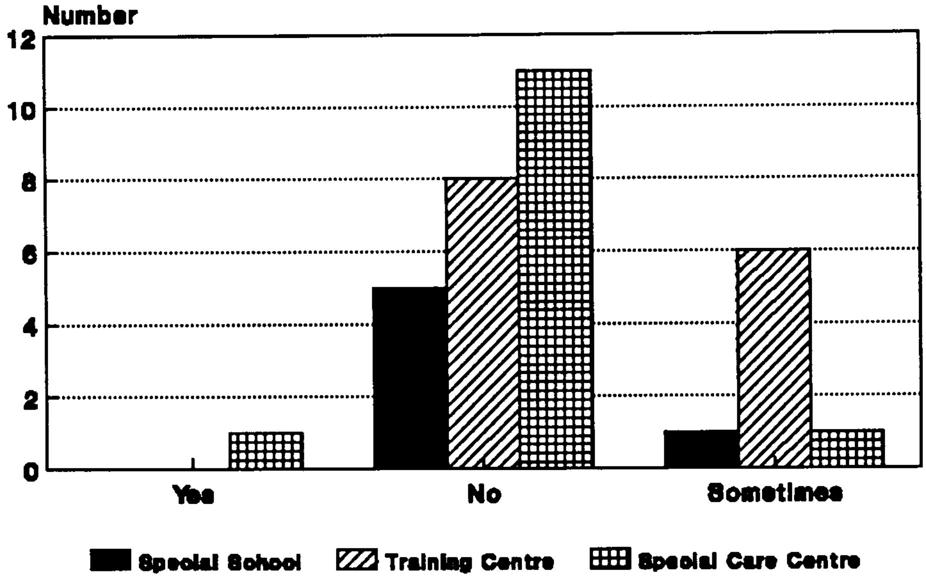


Nineteen of the 33 centres will indicate to the parents that a problem ought to be dealt with. Twelve of these use other services if parents fail to comply. The remaining 7 did not volunteer what alternative would be resorted to. Eight (24.2%) centres felt that they had no option but to request that the parents deal with the problem. Six of the 33 centres use only 1 health centre for referrals of this nature. No centres make use of specialist clinics to assist in this area.

QUESTION 4: Urgent Problems

Only 1(3%) centre can count on a doctor (a G.P.) in an emergency. This centre is residential. 8 (24.2%) had doctors who may be available to come and 23 (69.7%) had no doctor available. One Special Care Centre had not faced the situation and had no plan for the eventuality. This centre was excluded from this portion of the analysis. Analysis by type of centre is shown in Fig. 6.

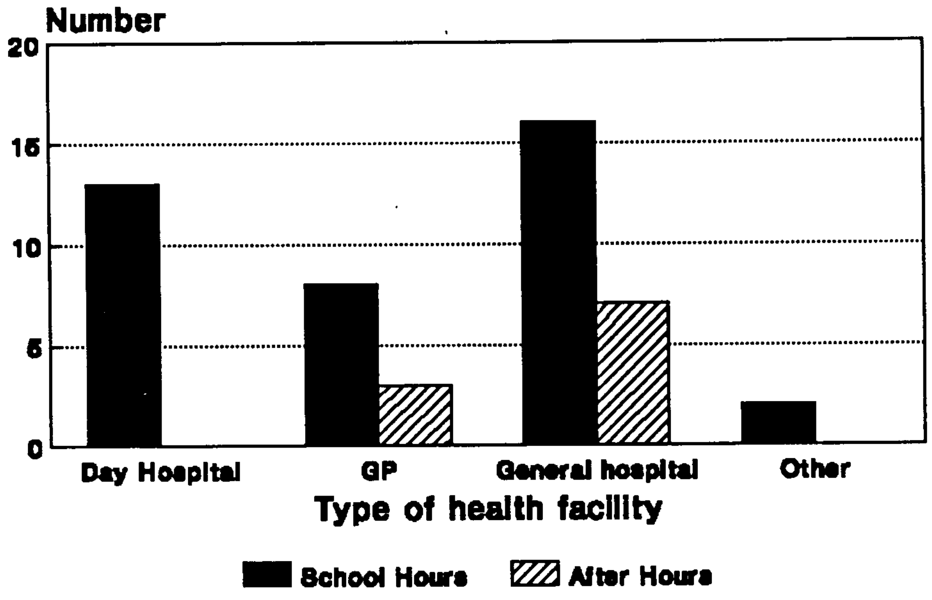
FIGURE 6
AVAILABILITY OF DOCTORS FOR EMERGENCIES



Number = 32

The health centres used for emergencies on weekdays are shown in Fig. 7. A district surgeon and a private clinic are the 2 centres not specified in the Figure. For 7 centres, the type of emergency dictates whether a general hospital is used rather than a General Practitioner or Day Hospital.

FIGURE 7
DISPOSAL OF URGENT PROBLEMS



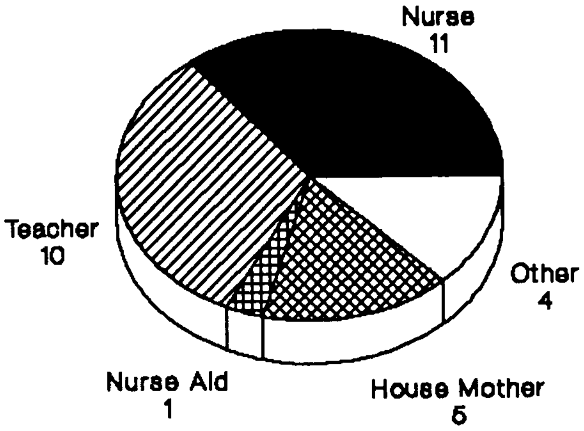
The 7 residential centres depending on afterhours emergency services use the general hospitals. Three which may have the services of a General Practitioner at the centre may take an emergency to the doctor's rooms.

QUESTION 5: Who accompanies the Children to Health Facilities?

The distribution of persons usually responsible for accompanying children to health facilities is shown in Fig 8. "Other" includes a variety of other staff members and, in one case, ambulance personnel take responsibility.

FIGURE 8

PERSONS ACCOMPANYING CHILDREN



Problems Experienced with Health Facilities

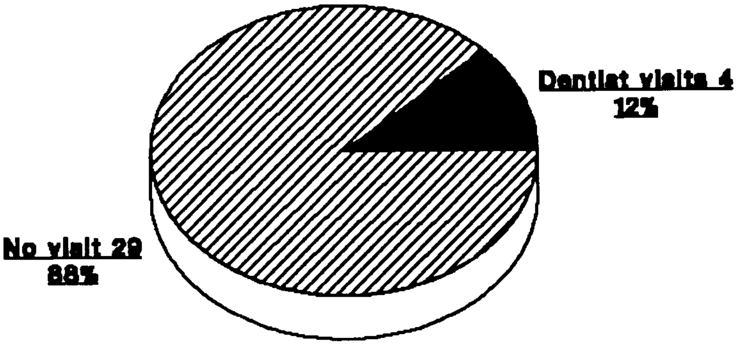
Fifteen of the 33 centres did not report any problems in the use of health facilities (3/6 Special Schools, 7/15 Training Centres and 6/12 Special Care Centres). The most frequent complaint was of delays in outpatient and X-ray departments (N = 9). Seven centres regarded poor reports as a problem and 5 felt that their children received inadequate management at the health facilities. Other complaints were that children were turned away at Day Hospitals (N = 2), difficulty getting parental cooperation (N = 2), discontinuous follow-up and hospitals not supplying medications to be administered at school (N = 2). One day hospital refused to see children without their parents and another would not treat children from a school because the children were disabled.

QUESTION 6: Visits by Dentists

Four of the 33 centres have a dentist visiting the centre. None of the Special Care Centres has a visit from a dentist and 2 each of the Training Centres and Special Schools have dentists who come to the centre. (Fig. 9) Three centres are for coloured children, and the other is the only black Special School. No centre for whites has a visiting dentist.

FIGURE 9

CENTRES WITH DENTISTS VISITING



Of these 4 centres 1 had a dentist on the premises every day and the other 3 received a yearly visit. In all cases this was a government dentist. No dentist received additional remuneration for these visits.

Centres with no Dentist Visiting

Of the 29 centres which did not receive a visit from a dentist 12 ensured that the children received a regular dental examination. Only 1 of these was a Special Care Centre and it was one of the 2 residential centres. 8 were Training Centres and 3 were Special Schools.

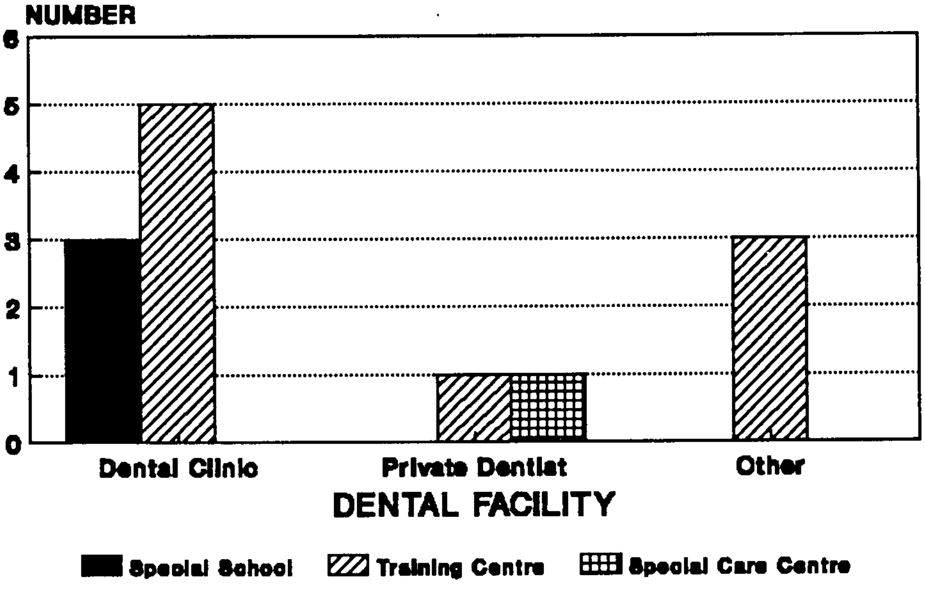
The distribution of the 17 centres not served by a dentist is shown in Table 7. Comparing the types of centre shows no statistically significant difference in the numbers.

TABLE 7: CENTRES NOT SERVED BY A DENTIST

	Number	Number of Pupils
Special School	1	340
Training Centre	5	392
Special Care	11	398

The analysis of where children receive their dental care in those centres with arrangements with dental services is shown in Fig. 10. One centre uses both the local dental clinic and a private dentist. The dental service at a local Special School is used by 1 Training Centre and 2 centres use Provincial Hospital dental services. The centre that depended fully on the services of a private dentist had only 10 children on its roll.

FIGURE 10
DENTAL FACILITIES USED BY THE CENTRES



No. of Centres = 12

How Many Visits to the Dentist do Children Make?

Three of the 12 centres using outside dental services had biannual visits for each child, 8 had annual visits and 1 was able to get each child seen only every second year.

What Improvements in Dental Services are Sought?

When asked about improvements the interviewees would like to see in health services to the centres, dental care featured frequently. Four special care centres felt that it would be best if the dentists visited the centre as the child would be most cooperative in familiar surroundings. Of those who used dental clinics 4 (55%) Training Centres felt the need for more frequent visits and 1 felt that the dentists needed more experience in handling the disabled. Seven out of the 13 Special Care Centres expressed the need for improved dental services. If a child needs a general anaesthetic for examination or therapy this proves a major logistic problem for 3 of the 7 Training Centres who have regular visits.

QUESTION 7: Visits by Community Nurses

Fifteen centres have community health nurses visiting them. 13 are visited by local authority nurses. One Day Hospital sister visits a centre and another centre is only visited by a Genetic Services nurse. The function of the local authority nurses is in most cases circumscribed, being confined to contraception (6), immunisation (5), Heaf testing (1) and genetic services (2). 4 make a wider use of the skills of the local authority nurse. School Health Service Nurses are not involved in the health of children in the Special Schools.

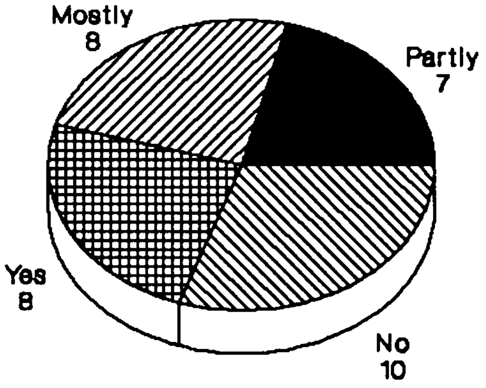
Three centres with no visiting doctor, no nurse and no regular review of the children receive visits from community nurses. One is confined to contraception and another to immunisation. 10 centres receive visits from none of the health professionals inquired about in the survey and do not have nurses on the staff. Seven are Special Care Centres representing 58,3% of these centres and 3 Training Centres(19%).

QUESTION 8: Satisfaction with the Services

The response to this question is shown in Fig. 11. Fig. 12. shows the responses of the nurses and heads separately. If the 3 negative comments are grouped together as "unsatisfactory" there is no statistically significant difference between the two groups' responses (p=0,22 Fisher Exact test).

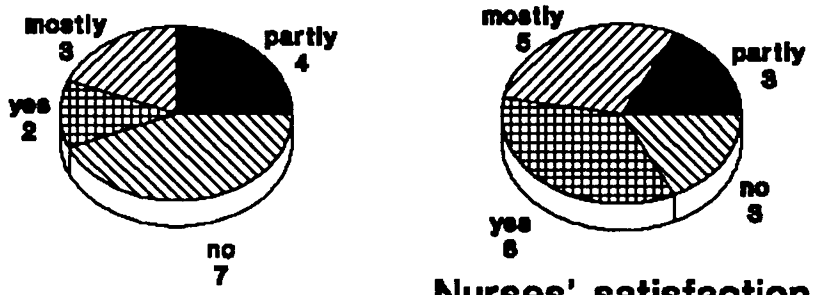
FIGURE 11

HEADS' AND NURSES' SATISFACTION



Satisfied = 8, Not satisfied = 25

FIGURE 12
SATISFACTION WITH SERVICES



Heads' satisfaction

Nurses' satisfaction

QUESTION 9: Improvements sought

The following were the improvements the interviewees felt were the most pressing for their centres. Four centres did not feel the need for improvements. The number of centres indicating a particular need is shown in brackets.

DOCTORS

- wish for a doctor to come to the centre(10)
- visiting doctor to deal with intercurrent problems as well as current duties (5)
- visiting doctors to see all children at some time
- a doctor available for problems in the hostel
- a visit by a Urologist
- uniformity in medical approach to the children

DENTISTS

- more access to dentists(4)
- regular dental inspections for the children(4)
- easier access to treatment and examination under general anaesthetic
- preventive dentistry service

NURSES

- need a nurse on the staff(2)
- need more nurses on the staff(2)
- nurse on the staff should be allowed to prescribe basic medications
- need a nurse on duty at the centre 24 hours a day
- nurse needs time to do health education with the children
- nurse needs assistance with handling the children and their equipment when using hospitals

ANCILLARY SERVICES

- need paramedical services(6), specifically physiotherapy(3), speech therapy(4) and occupational therapy.
- eye service at the centre(2)
- facilities for parent education
- sex education for the children
- staff education in problems of intellectual handicap
- more primary health care input into the centres(3)

HEALTH FACILITIES

- better communications from the hospitals(3)
- better awareness at referral centres of the special needs of the children(2)
- more records available to the centre's nurse
- visits by a multidisciplinary child development team to evaluate children(3)

- parents should not pay for the visit when collecting medication(2)
- quicker service(2)
- a regular outpatient time for children from the centres to be seen.

CHAPTER FIVE

CONSTRAINTS

The study, being based on a questionnaire, is dependent on the veracity of the respondent's answers. There are two main errors that may have clouded the accuracy of the results:

- the respondents may have altered the replies to suit their perception of the interviewee's role. Thus if the interviewer were thought to have influence with service providers, an undue emphasis might be put on problems and difficulties. Alternatively, if the questionnaire were seen as a type of audit, the lily may have been gilded.
- facts about the organisation of the children's health care may have been forgotten in the interview situation.

The following reliability checks were considered but rejected for the reasons given:

1. To interview a member of the board of selected centres.

   These members are likely to be less in touch with the day-to-day care of the children and to interview them might be construed as a slur on the ability and honesty of the initial respondent.
2. To check hospital records.

   Owing to the number of institutions and children involved this was considered impractical and would probably not yield the information sought.
3. To repeat interviews at selected centres.

   The initial interview may have had a sensitising effect as, soon after completion of the study, a number of changes took place in some centres rendering a repeat interview unreliable.
4. To interview a selection of doctors involved in the centres.

   Only 42% of the centres have named doctors involved in the children's care making a representative sample impossible.

The following factors support the veracity of the responses:

- when the idea of the study was mooted there was much enthusiasm from the authorities consulted;
- the positive response to the initial letter suggested that people wanted their problems known;
- the telephone call prior to commencement was an opportunity to inform the interviewee of the thrust of the questionnaire without giving the details of the questions. This afforded them an opportunity to marshal the facts and priorities in preparation for the interview but did not allow for detailed prepared answers;
- the researcher's role was spelled out in the initial letter;
- the length of service (mean 6,6 yrs) of the respondents.

CHAPTER SIX

DISCUSSION

6.1 COMPREHENSIVE CARE

The care of children with chronic impairments is multifacetted. Much has been written on the comprehensive care of chronically impaired children but much of the literature is situation specific, depending on the standpoint of the writer. Pless and Pinkerton (1975) concentrate on the psychological implications and identify three principles for intervention: education, counselling and practical provision. They emphasise that there is a common set of problems facing all children with impairments and these need to be addressed if psychological adjustment is to take place and equilibrium be maintained. This common thread has been shown in studies discussed by Pless with Perrin (1985) to have the following components:

- secondary psychological effects;
- impact on the family;
- the effect of community values;
- the need for financial assistance;
- the need for social and counselling services;
- the need for community education;
- having to face fragmentation and specialisation of services.

This point is reiterated by Stein and Jessop (1984) and Massie (1985) who argue that chronic impairment demands that the doctor move out of the traditional "curing" role to that of "caring". This requires that the doctor assess the biologic, behavioural and social manifestations of the impairment and see the positive and negative factors affecting each.

McInerny (1984), analysing the problem from the standpoint of an American Primary Care Paediatrician, sees three aspects. He sees the paediatrician as 1) committed carer 2) family supporter and 3) someone who helps the child adjust to the disability.

The pivotal role of the family in care of the chronically impaired child is emphasised by many authors (McInerny 1984, Sabbeth 1984, Younghusband 1970) and comprehensive care demands adequate assessment of the effect of the disability on the family and the family on the disability.

Stein and Jessop (1984) highlight two other areas that make up comprehensive care of the child. Firstly, there is the preventive aspect. This includes those primary preventive measures which are essential parts of any child's health care such as immunisation and screening tests. Health education assumes a greater role with disabled children as the range of issues is wider including genetic counselling and planning for the future. To fail to address these is to fail to prevent problems later. Similarly early recognition and treatment of maladjustment would be an example of secondary prevention. Stein and Jessop use the term "anticipatory guidance" for these aspects. The second important part of comprehensive care these authors highlight is that of advocacy. With the array of impediments (statutory and societal) facing the child with an impairment and the family, professionals need to be willing to act on behalf of them and smoothe their life path where possible. This requires good communication between family and health professionals.

In the light of these approaches, comprehensive care may be defined as:

> care that assesses and addresses the physical, psychological and social state of the child, including all factors that work for and against his or her complete attainment of innate potential.

It will be understood that this is a dynamic concept that needs to take account of the child's specific problems and strengths in the light of circumstances prevailing at a specific time, and must be appropriate to the child's age and developmental level.

It is worth spelling out all the facets which need to be taken into account as, when planning health service intervention, the role of each part in addressing these factors can be defined. In a series of studies assessing the care of children with chronic illness (discussed in detail in Section 6.3), the authors used a questionnaire evaluating it under the following headings:

- evaluation and treatment
- advice (on daily living)
- future planning
- genetic counselling
- coordination
- support (emotional, practical)
- acute care
- well child care

The health professionals and services studied all have a role in the delivery of comprehensive care to children in the 33 centres visited. The discussion which follows examines the implications of the findings of the study for each group of professionals and for the health facilities and services. How well set up is the present situation to provide optimal care? What are the present strengths which can be built upon, and where are the deficiencies which need to be addressed?

6.2 POPULATION GROUPS

As indicated in Chapter 1 provision of facilities for black and coloured children with disabilities in South Africa has been shown to be insufficient (van der Westhuizen 1990, Coordination Committee 1987). This study confirms a discrepancy in the provision of services between population groups with fewer than 10% of places being at centres for blacks. This is 20% of the number of places for whites and 16% of that for coloured children. For physically handicapped children the proportion is nearer 10%. Special Care places for blacks exceed those specifically for whites but the non-racial centre has a large proportion of white children. Analysis of preliminary results of the 1991 population census (Central Statistical Services 1991) shows that there are more black children under the age of 20 than there are white children in the area under study emphasising this discrepancy in provision of places and confirming a worsening of the situation.

The census figures for coloured children show that there are nearly twice as many coloured children under the age of twenty years as there are white children. In absolute numbers this study has shown that places for coloured children exceed those for whites by 227. This is true for all types of centre and yet the studies of Grover *et al.* (1987) and Eichhorn (1986) suggest that these are still inadequate at least for intellectually retarded children. Seen as a proportion, the availability of places is significantly lower for coloured children. Further analysis of the demography is beyond the scope of this study but should be done to promote appropriate resource allocation.

Some centres in the area are now non-racial though numbers are small (138 children in 2 centres). Numbers by population group in these centres were not sought. At the time of the study, first steps were being taken into desegregating Training Centres though the number of children who had crossed the recently-breached divide was small and would not significantly alter the overall figures.

Only one of the 5 centres for black children is provided by the state as opposed to 7 out of 9 for white children and 13 out of 17 for coloured children. In the latter case this reaches statistical significance (p = 0,039 Fisher Exact).

Only one of the centres for black children has a nurse. This the special school. All the Training Centres of equivalent size to the only black one have nurses. This Training Centre is run by the Department of Education and Training. Although there was no statistical significance in the difference between centres by population group regarding visiting doctors, it is important to note that only one centre for blacks has a doctor visiting as opposed to half of the other centres.

For those centres without doctors, the use of facilities for medical opinions does not differ between the population groups. No centre for white children is visited by a dentist. This seems to be due to the assumed use of private dentists (see Section 6.4).

This discussion of the differences in provision of services to the centres with respect to population group is relevant to the provision of comprehensive care for the children in the centres. These differences should be borne in mind during the subsequent discussion of the role of the various professions in the care given at the centres.

6.3 THE DOCTORS

There has been much debate as to the role of doctors in the centres for the handicapped. Smith *et al.* (1969) showed that where there was no regular medical input many diseases were undertreated. However community-based rehabilitation schemes have, in some cases, reduced the burden of handicap with minimal input from doctors. The trend for intellectual handicap to be seen as a social problem rather than medical has removed the doctor from the primal role in the care of this group of disabled persons.

Sulkes (1989) sees the doctor's role in day centres for children with disabilities as:

- screening
- assessment of admissions
- staff education
- liaison.

The doctor is seen as part of a team to ensure comprehensive care for the child (Polnay and Hull, 1985 p231ff). Lewis (1990) describes a visiting paediatrician's role in the following terms:

> "It is about providing health care to individual children and support to their families. This entails working in a team with nurses and therapists based at the schools. It entails understanding how schools work, and the anxieties of staff about the children they teach. It also demands the ability to think of a child's medical condition in terms of how it affects his life in school, and to interpret this to his teachers both individually and by taking part informal in-service training courses for teachers and other education staff. ....Finally,...... (it) is cooperating with health service managers in planning for better provision of health care services within the school, and advising education authorities on the adaptation of the school environment to children's needs."

Polnay (1985) recommends an annual review of each child by the school doctor who also should see every child on admission to the centre and Lewis concurs stating (ibid. p803):

> "Regular review of children who are in special schools is best carried out in the school, by a doctor who is part of the school team as well as the health care team, and who can see the child's health care in the perspective of the school and the community."

Walker (1984) recommends that the doctor be involved in schools at all points in the child's care, ie. identification, referral, evaluation, re-evaluation and daily care. She writes:

> "The best care in schools for these children will be accomplished only by a team effort among the parents, pediatricians (sic), and school personnel."

The main contribution of the doctor is medical care as this is the thrust of medical training. The doctor, in essence, uses his or her clinical skills in the health care of the children but analyses the individual's problems in the context of the school, family and society. This domain is not exclusive to the doctor. The role of nurse as clinician is discussed in Section 6.5 below.

This study has documented that the majority of centres in Cape Town and environs do not have regular visits by or to doctors for the children under their care. Overall this represents 30% of the 3480 children in the centres. Thus 75% of black children, 40% of coloured children and 10% of white children have no regular contact with a doctor through their centres. Of those centres which do have regular visits, the majority (63,2%) do not have annual reviews of the children. Thus 795 (22,8%) of the children have annual reviews arranged by 7 centres in all. These reviews are undertaken by paediatricians or doctors with an interest in cerebral palsy in all but 2 of the centres. These 2 centres (61 children) have reviews outside their walls by Day Hospital medical officers and a GP. The form and range of these reviews was not a subject of this study but is worthy of investigation. One factor which may result in an underestimate of the proportion of children receiving annual reviews is the fact that fully 55% of children at "white" Cerebral Palsy Schools are there because of learning disabilities (Potgieter, 1991), and they have less need of a doctor in the centre reviewing their progress.

The most common function of the doctors in the centres is dealing with problems arising in the management of the children but fewer than half of the centres are able to use their doctors in this way. The doctors are mainly specialists or non-specialists with a particular interest in cerebral palsy. Of these, the orthopaedic surgeons, geneticists, psychiatrists and the ENT surgeon would be expected to deal purely with one aspect of a child's care and would see only those children who were felt to need their expertise.

The study does not directly tackle the question of whether the doctors in the centres are able or willing to be part of a comprehensive service to the children. For the orthopaedic surgeons their ubiquity at the centres for the higher IQ physically impaired children would suggest that this aspect is covered. All these surgeons are associated with university departments.

The comprehensiveness of the service of the paediatricians and the medical officers is less easy to define from the data. At the school where the paediatricians only see new children it is assumed that all children have another doctor who takes primary responsibility for reviewing them. At others, the paediatricians only see children who are already known to them. If the main concern of the visiting paediatricians is trouble-shooting as the figures suggest, then the service within the centres is unlikely to be comprehensive.

It would be reassuring to think that the children not reviewed regularly at the centres are receiving the reviews elsewhere. There is little data on the care given to disabled children by GPs and hospitals in South Africa but experience in other countries suggests that this is often inadequate.

With respect to the hospitals, the Developmental Clinic at the Red Cross War Memorial Children's Hospital mainly reviews preschool aged children with developmental disabilities and reports a high level of missed appointments (Annual Report, 1990). The

Neurology Clinic at the same hospital has over 2000 follow-up visits per annum but the proportion of children who come from the centres is not known. Likewise the Cerebral Palsy Clinic sees many children every year but the number of children from the centres and the comprehensiveness of the care has not been researched (L. Arens - personal communication). Doctors from all these clinics are amongst those who visit the centres. Some nurses at the centres reported that children referred from these clinics and similar ones at Tygerberg Hospital did not continue being seen by the assessing doctor.

Lachman and Zwarenstein (1990), in a study in Mitchell's Plain, showed that a referral hospital dealt with an estimated 29,8% of chronic illness and that 10,7% received no ongoing care. Only 20% of these disorders are dealt with by General Practitioners and only 30% of respondents said that they had an appointment to see a care provider for the condition. Specific figures for disability as defined in this study are not given. Molteno (1990) gives details of the Developmental Clinic at the Red Cross War Memorial Children's Hospital in Cape Town. This clinic is staffed by a multidisciplinary assessment and treatment team and deals mainly with the preschool age group. Friedlander and Power (1982), in a study in Heideveld, Cape Town, found that behavioural problems and squints were inadequately dealt with for children with profound and severe mental retardation in the community. Many parents also had little insight into the child's condition which may reflect poor communication by or inadequate contact with doctors. Similar results were found for children with cerebral palsy. Although dealing with all age groups the studies of Disler *et al.* (1986a,b) showed that medical and ancillary care hardly penetrated the homes of those with locomotor disability. Most pre-school age children were not in any kind of daycare facility where this might have been available.

Experience elsewhere suggests that it is easy for care by doctors of children with disabilities to be inadequate and uncoordinated with uncertainties as to who is responsible for the child's care. In 1974 Kanthor *et al.* reported results of interviews with parents of children attending a specialist spinal defects clinic. They found the technical matters were well covered but advice to the parents and discussion or planning for the future were deficient. Acute care and well child care were felt mainly to be the responsibility of the primary care physician -- but in 25% of cases this did not take place. The authors called for one doctor dealing with the children to be the coordinator of care.

Pless *et al.* (1976), in a survey of care in New York state, quote a study of primary care doctors in Michigan in which 34% of doctors never saw children with mental retardation. In their own survey they found that "primary care physicians do not play a major role in the management of children with chronic illness with respect to counseling (sic), advising and coordinating other services". They feel that services to children with chronic impairments should take into account the similarities of the children and be arranged on a regional basis.

In a study of an arthritis clinic for children published in 1978, Pless *et al.* showed duplication of some aspects of care but, more seriously, neglect of genetic and general advice and future planning. They stress the importance of annual comprehensive reviews and highlight the factors which inhibit the primary care doctor from taking on this role, namely time, money and attitude. The alternative they suggest is a multidisciplinary centre.

Ayers (1984), in the study already quoted (Chapter 1 p2), found that very poor information on services was acquired by the families of children with disabilities. Importantly, teachers were found to be the best at giving useful advice to these families.

Palfrey *et al.* (1980) examined the care of children attending five hospital specialist clinics. They found that one third of children had no primary medical care and used emergency facilities for acute illness. 38% had unattended symptoms which were unrelated to the major chronic impairment. Stein *et al.* (1983) found that non-biomedical aspects of the children's care were poorly covered by health services. As with Palfrey (1980) they found that acute care was often not attended to by a named facility or person.

The Warnock Report (1978) in Britain recommended that a "named person" be responsible for coordinating the child's care although this was not necessarily the doctor and the authors felt that during the school years, this person should be in the school. This is now implemented under the Education Act. Battle (1972), in the U.S.A. context, contends that the paediatrician ought to be the "ombudsman" of the child's care.

A more recent survey (Liptak and Revell, 1989) of doctors' and parents' attitudes to the care the children receive shows that 74% of practising physicians (paediatricians, family physicians and G.P.s) felt that the doctor in the community should be the case manager although in 51% of cases it was not clear who the responsible person was. There was a large discrepancy between the doctors' and the parents' concepts of the information given concerning the diagnosis and care of the child. The problems of cost and time that reduce the chance of the community doctor fulfilling this role are again highlighted .

Polnay outlines a comprehensive role for the school doctor in a British context in a very practical manner as follows:

- To see children before they start school in order to get to know them and their families
    - to discuss the implications of the child's medical condition with teachers, therapists and nurses
    - to establish a link between the school and the hospital paediatrician looking after the child
- To see the child annually to
    - review medical problems affecting education, vision, hearing, epilepsy and its treatment

  - review mobility with physiotherapists
  - review sensory problems
  - discuss with parents any problems arising in the home
  - review the diagnosis in doubtful cases
- To provide medical contribution for statement of special educational needs
- To provide advice to the careers service or social services department on school leaving about
  - effect of medical condition on employment
  - need for medical care after school leaving
  - give the same to young person or his family
  - to provide day-to-day medical management of the child at school and to give support and advice to staff and parents

This approach may be applied to children in special centres.

Although this study has shown that fewer than 22% of children in the centres are reviewed regularly it needs to be considered whether they are not the best place for these reviews to take place. The advantages are manifold:

a) the review would take place in most cases in the presence of the child's most regular health professional -- the centre's nurse. This enhances continuity, regularity and consistency of care and reduces communication lapses (Crossland *et al.*, 1986);

b) care is arranged from one site rather than a number of professionals acting independently for the child;

c) the education of the child being of paramount importance, health care on site emphasises the link between the two and puts the latter into perspective. To involve the teacher in the health evaluation is considered important to comprehensive care (eg. Walker, 1984). The teacher can give valuable insight into behaviour and possible sensory abnormalities. The child also misses less classroom time if seen at the centre;

d) the centres are located for the most part much closer to the family's residence than the specialist hospitals. Transport difficulties and missed appointments would be reduced;

e) having the parents present in the school context enhances understanding and elucidation of problems which benefits the child;

f) some centres have paramedical therapists on the staff or visiting and the chances of multidisciplinary input of professionals regularly involved in the child's management is greater than at most other sites. In centres without this team, therapists could attend to advise. This concept has already been begun by a team from the Care and Rehabilitation Centre at Lentegeur Hospital (C. Chouler - personal communication) and is one of the recommendations of the Report of the Coordination Committee for the Year of Disabled Persons (1987);

g) at the time of writing, services at Cape Provincial hospitals are being reduced to cut costs (van Niekerk, 1991). Staff numbers are being reduced and appointments for some clinics are only available months ahead. To have reviews at the centres would probably reduce costs for the hospitals and would streamline care for these children;

h) many doctors are already visiting centres and this existing service could be the nucleus of a more complete service to all centres;

i) as comprehensive care demands understanding of family relationships and most families in lower socio-economic groups do not have family doctors (the health professional most likely to be responsible for ongoing family care), professionals at the centre may be best placed to provide or arrange help and support in these areas.

All these factors have their main force for the poorer sectors of the community and those for whom access to services has been problematic but it should be considered in all contexts.

The drawbacks to such a system are mainly of a practical nature. The centre needs consultation space, an adequate records system and a designated contact person, preferably a nurse. As the centre is not a health facility, ancillary services from hospitals (such as Electroencephalography) need to be used. Woods (1983) has pointed out the value of the doctor having a foot in the hospital to expedite and regularise use of the hospital's facilities. At present there are many barriers to doctors at state hospitals seeing patients in other institutions on an official basis and any coordinated service would need their presence to be given official sanction. The fact that 6 paediatricians from state hospitals are already providing a service is encouraging. It suggests that, given the right conditions, they and others would be willing to provide a more complete service.

6.4 THE DENTISTS

Children with intellectual and physical impairments have at least as much need of the services of dental professionals as other children. Whether there is an increased prevalence of dental caries in these children is debated with studies showing conflicting evidence (Nunn, 1987). Poor dental hygiene and periodontal disease have a higher prevalence than in the general population (MacLaurin, Shaw and Foster, 1985). Certain groups of children with impairments are at greater risk of dental disease. Children with Down's syndrome, for example, have a higher prevalence of periodontal disease and those with some types of cerebral palsy have orthodontic problems (Nunn, 1987). A study in schools for children with epilepsy in Cape Town showed a very high prevalence of dental disease in those with poorer services (Hartshorne *et al.*, 1989). It is also well established that these children often have extractions rather than therapy aimed at preservation of teeth although this tendency is being reversed in some places (Mellor and Doyle, 1986).

One of the main factors which has prevented children with impairments receiving optimal dental care has been difficulty with examination and treatment. The causes for this relate both to the child and the practitioner. Many children with intellectual impairments react poorly to strange situations and unexpected interactions and dental examinations are often perceived as very threatening resulting in complete failure on many occasions. Children with spastic quadriplegia have abnormal oral and jaw reflexes rendering intraoral examination and treatments well nigh impossible without anaesthetic. Dentists and other dental professionals require special skills to overcome the problems created by the special needs of the children. The wide variety of additional medical problems found in children with disabilities (eg. heart disease in Down's syndrome) has caused many dental practitioners to shy away from involving themselves in their care. Access constitutes another factor militating against regular and complete dental care for impaired children. This relates both to the site of the place of examination and to the structure of the chair and the rooms. Another factor which can be identified is distance from the dental service where special services are available. Leahy and Lennon (1986) cite maternal anxiety as another factor working against adequate dental care for handicapped children.

The study has shown that half of the centres in Cape Town have arrangements for the children to have regular dental consultations. This covers the majority of the Special Schools and Training Centres but only 1 of the 12 Special Care Centres. One of the Training Centres and the one Special School without dental cover cater in the main for white middle class students and parents are given the responsibility for using dental services. Experience elsewhere has suggested that this is difficult to obtain in private practice (Nunn and Murray, 1988). Of great concern is the lack of dental care for the most severely disabled children populating the Special Care Centres. Only 10 of the children in Special Care Centres are seen by dentists under the auspices of the centre leaving 398, the largest number and by far the largest proportion of the 3 types of centre. These children have the most need of dental care, and often need specialised care, but at present would appear not to be receiving it readily.

One Special School has facilities on site and is visited by a team from the Dental Faculty of the University of the Western Cape. This facility has been specially designed for the dental care of children with cerebral palsy and is staffed by dentists, oral hygienists and dental students (Y. Moola - personal communication). This facility is also used by children from a neighbouring Training Centre. No other schools have facilities specifically for dental use on site. The dental services used by the other 12 centres are not specifically geared for disabled children and the interviewees pinpointed this as a drawback. It is encouraging to discover, though, that most of the children in these centres are reviewed at least annually.

Much has been written about delivery of accessible, available and appropriate dental services to children with disabilities. Various attempts to solve the problem have been described.

i. **To overcome the child's fear:**

The emphasis here is either on treating the child in an already familiar environment such as the school, or familiarising the child with the clinic setting. Mobile dental clinics have proved useful in achieving this as they can come to the school and the children can be introduced gradually to the service (Dane, 1990). To have familiar faces, especially the parents, has proved most important (Pool, 1981). Lindemann and Henson (1984) showed that training personnel to handle the child in an appropriate manner promotes the chance of a successful examination. Parental fear should also be addressed (Leahy and Lennon, 1986).

ii. **To train staff adequately**

In the U.S.A. there is a major programme to teach dental students about handicap and encourage undergraduate experience in treating children with disabilities (Salley, 1980). Block and Walken (1980) demonstrated that such a programme reduces the students' fear and anxiety and this can be expected to increase the chance of their taking on the care of these children in their practices. Nunn and Murray (1988), in England, found that dentists who had been through such a programme were more likely to treat disabled children in private practice than those who had not. Relatively minor adjustments to procedures and positioning can make successful management much more likely (Gallagher 1980, Morgan 1979). At the University of the Western Cape, dental and oral hygiene students work with children with cerebral palsy at one Special School to expose them to children with disabilities.

iii. **To improve accessibility**

Nowak (1984) has shown that providing dental care to the disabled in a community setting reduces the prevalence of dental diease. British experience has suggested that parents prefer the child to be seen in community clinics or private surgeries, rather than in hospitals (Manley and Pahl, 1989), and Mellor and Doyle (1987) show that a service set up in the community and geared for disabled children produces better treatment, fewer problems and better attendance. It also reduced the need for general anaesthetics. Locally, Moola has demonstrated a similar efficacy (Personal communication). Mellor, Pool *et al* (1981) describe a mobile service based at Guy's Hospital in London which travels to Special Schools. This is backed up by oral hygienists in the schools and is well used. The connection with the hospital is considered valuable in providing a continuum of care for those children who need more specialised procedures or general anaesthetics. Dane (1990) describes a similar system in the U.S.A.. This kind of programme also overcomes architectural barriers.

Design of new dental facilities should always ensure easy access for disabled persons.

University Dentistry departments have taken a leading role in providing dental services to the disabled and South Africa is no exception to this. This has often been by default because of the barriers (structural, financial and attitudinal) to other providers fulfilling this role but also because of the wide range of disabilities and the wide range of associated dental disorders. There are advantages to this. Barnett and Ziring *et al.* (1988) describe the close liaison between a Developmental department and the Dentistry department which allows an efficient and comprehensive service to be provided in the context of education and research. Universities usually have state-of-the-art equipment and expertise and fulfil the all-important educational role. They cannot and should not aim to serve the whole disabled population and community services need to be developed.

Services are often inadequate even in developed countries. In Australia only 18,5% of handicapped people in institutions received care in 1984 (Brown, Aitken and Walsh, 1984) and in Denmark, if an institution for the disabled does not have a dental clinic, dental care is poor and disease more prevalent (Schwarz and Vigild, 1987).

Against all this discussion on special services for the disabled must be held the concept that disabled people in the community should be seen to be there and general dental services should be adjusted to allow access to those disabled persons who do not need all that different an approach from their normal coevals. This certainly is the best option for Cape Town where money for services such as mobile clinics is not readily available, universities have limited service objectives and there is in place a network of community dental clinics some of which are already being used by centres for disabled children. In order for Dental Clinics to fulfil their role in the dental care of the disabled, administrators need to acknowledge that more time per child needs to be allocated.

Discussing school dental health programmes in South Africa, Rudolph and Gilbert (1987) consider a school based programme to be most appropriate and cite the gross inequalities in dental services to the various communities as being detrimental to other forms of community care. In the service they describe, a mobile dental unit (supported by private industry and commercial companies) is used. Whether the same sources would be as enthusiastic in supporting services to disabled children needs to be tested.

Preventive dental care constitutes a major strategy in dental health. This is especially true for handicapped children who have a number of factors which add to the risk of dental disease. Feeding difficulties result in retention of food debris in the mouth and decreased saliva if insufficient liquid in drunk. High carbohydrate meals are common and sweets may be used to defuse difficult behaviour. Many medications which children with disabilities are more likely to take regularly contain sucrose as a base. Phenytoin, often used to control seizures, can produce gingival hyperplasia. Teeth may be damaged by trauma and seizures. Hyperactive oral reflexes can make toothbrushing impossible without special manoeuvres.

Thus vital to the ongoing dental care for handicapped children is promotion of the four main preventive strategies: diet, brushing of teeth, fluoride (vital in the Western Cape) and flossing (McIver and Macken 1979). Dental education for the children is part of the curriculum in most centres for the disabled. One fact found serendipitously during the interviews was that many centres are visited by oral hygienists who appear to be the front-line dental professional in these circumstances. However they do need adequate back-up by dental practitioners who manage any problems hygienists might identify. It is not clear if these hygienists are acting purely in an educational role in the centres. Their number and effectiveness are worth researching in detail. Oral hygienists in disadvantaged communities had not had much impact in 1984 (De Villiers, 1984 p10). Hartshorne *et al.* (1989) in their study of children with epilepsy in the Cape emphasise the need for annual reviews, education and regular preventive measures including measures to prevent dental fissuring, which they found to be a major problem in certain groups.

6.5 THE NURSES

Nurses are the backbone of many health services and in schools for the disabled they represent the front line of health care when present. This study has shown that nurses in these centres mostly work alone and are not part of the School Health Services or any other body that might coordinate their service of provide support. The mean of 8 years of service at the centres suggests that the nurses are committed to working for the children under their care. This is reinforced by the fact that nurses in the 8 centres with residential facilities continue to undertake burdensome afterhours rosters to ensure health cover for the residents.

The majority of the nurses had gained their experience with disabled children at the centre. Many had attended seminars and courses on subjects such as epilepsy since taking on their jobs but there is no systematic training for these nurses. Diplomas such as Paediatric Primary Health Care, Community Health, Psychiatric and Orthopaedic Nursing are potentially very useful for nurses taking on this role and many nurses have entered the schools with these qualifications. Disturbingly, the skills acquired could not be used under some authorities. This results in unnecessary use of other sources of primary care. For example, one nurse with a Community Health Nursing Diploma had to send children to the Day Hospital for treatment of scabies. A number of nurses are in the process of doing or hoping to do the Community Health Nursing Diploma as they feel that their work needs the skills imparted by that course. The direct input on childhood handicap in the 1 year course is not extensive and mainly relates to identification and referral but an emphasis is put on family support (V. Miles- personal communication). One S.R.N. had done the Nursing Administration Diploma, a background that could possibly be useful for the role the nurses are taking on in the centres.

Judging from the responses during the interviews, the nurses take on a number of roles in the course of their work. These include;

- organising the doctors' visits
- organising visits to doctors and dentists
- seeing ill children and arranging their care
- accompanying children to health centres
- routine health checks
- seeking out new medical sources of care
- after hours cover for emergencies in the hostels
- records keeping
- liaison with community and genetic services
- involvement with routine child care such as feeding
- health education for the children
- advising parents
- storing and administration of medication.

Which roles are taken on and how time is allocated to them varies between centres and was not studied. In the U.S.A. a study of a school nurse's time when involved with children with special health needs showed that 50% of it was spent on direct service to the child leaving little time for all the other necessary activities (Cowell, 1988).

Despite the wide range of roles the nurses are taking on there is one glaring omission. Despite the prevalence of hearing and visual deficits in children with physical and mental impairments, there is no routine screening of these senses in the schools and training centres. This, combined with the relative lack of regular review, is of concern and warrants further investigation. It may be that screening is undertaken elsewhere but as this screening is done for children in mainstream education at the schools by school nurses, this is unlikely. Screening has been identified as an omission from the care of children with disabilities by others (Stein, Jessop and Riessman 1982).

Community nursing services are the other source of nursing expertise available to assist the disabled. In Cape Town in centres for the disabled the community nurse's role appears to be a very limited one in the light of this study's findings.

Fifteen centres representing 953 children, 308 of whom are the most severely disabled in Special Care Centres, do not have a nurse in daily attendance. Only 3 of these centres have local authority nurses visiting quarterly and at but one of these is anything more than immunisation or Family Planning done. Thus community nursing services of a more comprehensive kind are reaching a mere 18 of the 953 children. One centre caters for a wealthy middle class white group in the main where this service may be less essential but, for the rest, this deficiency represents a lost opportunity to prevent and treat problems in the most disabled and disadvantaged groups. At present in Cape Town City Council areas disabled children are seen by health visitors on a referral basis only and seeing children in the centres is not considered to be their responsibility (J. Dekenah - personal communication). Community Psychiatric nurses also can only take on work with mentally handicapped children on a referral basis (K. Lucas - personal communication).

The community nurse is potentially a key player in the comprehensive care of disabled children. She can be seen as a go-between for parents and health services, representing the parents to the health services and vice versa. This mediating role is of value to workers in special schools and centres where she can offer advice, hear about and assist with problems and mobilise community resources (health and other).

Sines (1985) gives a detailed analysis of the professional role of the community nurse in the care of the handicapped. The following areas of function are enumerated:

i. **nurse assessor**, to gather information on the child's needs and abilities;

ii. **nurse clinician**, to treat medical problems and refer where necessary;

iii. **nurse therapist**, to assist in therapeutic interventions such as behaviour modification or physiotherapy;

iv. **nurse manager**, to ensure good communication between professionals and to keep adequate records;

v. **nurse adviser**, to advise staff on the care of the disabled;

vi. **nurse counsellor**, to counsel families and disabled children especially in the adolescent years:

vii. **nurse coordinator**, to ensure that all services working for and with the child and family are efficiently used;

viii. **nurse educator**, to inform the public and other professionals about handicap;

ix. **nurse mediator and befriender**.

No other professional is equipped to take on these roles and the functions discussed are essential to comprehensive care for the majority of disabled children and their families. The clinical side of her role should be highlighted. In the present setting where many centres are not visited by doctors, this role takes on an added importance. Indeed, where doctors do visit but do not or cannot provide a complete service, this role may be significant in ensuring care. A nurse with some clinical training may be as much use as many a doctor who has no special knowledge of the needs of children with disabilities and thus might fulfil a role far beyond her present status. Thus, where suitably experienced and qualified doctors are at a premium (and this may apply in Cape Town) the nurse (given adequate staffing levels and remuneration) can take on a very useful clinical role to the benefit of the children.

The community nurse can be the one professional who sees the child both at home and at the day-centre and can promote ongoing and consistent therapy at both sites. A variation of this is suggested by Woods (1983 p26) in which the school nurse takes on responsibilities for the children at the school and beyond its walls.

Another group of nursing professionals not at present having a role in the centres for children with disabilities is the Nursing service of the School Health Services in the various (racially based) departments. These nurses have community nursing skills as well as much experience of the school-going child and the dynamics of school life. A liaison role similar to that described by Polnay (1988) for the school doctor (discussed above on p69) could be envisaged without the more specialised impairment-related clinical evaluation. These nurses are also equipped to deal with many paediatric medical problems.

In the U.S.A. community nurses participate in day centre evaluation of children's special educational needs and are considered invaluable in determining how the child's needs can best be met (Cullinane and Shishmanian 1989). They are not used in this role as much as they could be though (Crossland and de Friese 1986). They also have the mediating role described above, interacting between the wide range of professionals and "related services" mandated under PL 94-142, and the parents and the school (Steenson and Sullivan, 1980). In the local context, the centre's nurse could be of value in this role and indeed already partly carries it out.

Given the repeated assertions of failure of comprehensive care and communication between parents and doctors described in Section 6.3, what more important person involved in the medical care of disabled children is there than the nurse? She is the professional whose basic abilities are geared to caring (in its broadest sense) and whose skills could be enhanced to underpin a comprehensive service so lacking at present.

6.6 PAYMENT

A coordinated service in the centres would have to take into account payment for service rendered. At present some doctors are paid and others are not though the study did not quantify the proportions. This aspect cannot be isolated from all the other considerations necessary in setting up services as it would be the result of the coordinated interaction of the various stake-holders in the health and welfare of children with disabilities. There can be no escaping the conviction that care of children with disabilities has primarily to be the responsibility of the state if complete care is to be given. Experience cited throughout this discussion shows that voluntary work and market forces will not achieve this.

In the United States of America where PL 94-142 mandates that care be provided by the local education authority, those authorities would pay for services at a rate negotiated with the service provider. In the British context, the professionals are state employees. It would seem that much of the work done within the centres this study describes is done on a voluntary basis which, while laudable, is an uncertain base on which to build a service.

6.7 INTERCURRENT HEALTH PROBLEMS

6.7.1 Non-urgent

For non-urgent intercurrent problems experienced by the children, most centres depended on the parents to ensure that the problem was dealt with. In most cases other facilities were resorted to only if the parents failed to respond to the request and for 24% of the centres this option did not pertain. The heads and nurses in the centres catering for the more deprived communities felt that this was a drawback. There is support for this view in the literature. Crossland `et al.` (1986) in the U.S.A. found that more than 40% of children referred by school nurses had no evidence of parental follow-through. A quarter (5 out of 19) of centres which depended on the parents mentioned this as one of the 3 priority improvements they sought. Informal discussion has suggested that this may be an even greater need than these figures suggest. It is well-known that the poorer sections of the community have less access to health care and are less likely to seek it. Aggravating this in the case of the children in this study is the tendency for disabled children, especially the intellectually retarded, to respond poorly to unfamiliar environments. Many a parent suffers agonies in hospital waiting rooms before the child is seen and then has the additional embarrassment of an uncooperative child for the doctor to see.

At present doctors at the centres have only a minor role in dealing with intercurrent health problems with only 6 centres able to use their doctor in this way. There are 2 centres where the doctor fulfils this role fully. Both have a single doctor on the premises daily and are Special Care Centres. Neither of these doctors is a specialist.

What role can and should the centres play in management of non-acute intercurrent health problems? Two main options should be considered:

1) **The centre deals with intercurrent problems**

   It needs to be considered whether, when the child is in a centre where health care is part of the service, this facility should be used on a wider basis. In many (if not most cases) the school nurse should be equipped to deal with the commoner problems. (See Section 6.5) It should be possible for her to screen out the more complicated cases for the doctor to see at her discretion, preferably with the parents present. This overcomes the frequent complaint that the parents do not take the nurse's referral advice and no communication is received from the referral health facility. It also overcomes the anxiety that prevents many parents using other health facilities. On the negative side, some nurses expressed the fear that, were this option more easily available, parents would take the opportunity to hand over responsibility for their children's health to the centre. The validity of this argument is doubtful and such behaviour could be countered if met. The lack of dispensing facilities would be another disadvantage of this system. How frequently a centre-based primary health service such as this would be used is unknown.

2) **Referral centres become better suited to provide a service to people with disabilities**

It has to be considered whether providing "special" care for a disabled child is the correct approach. Many would consider it more appropriate to alter the health facilities to suit the disabled child better. Ideally all impediments (structural, attitudinal, parental) to the child using "normal" facilities should be removed. The centre and the professionals working there have a role in empowering the children and parents to recognise the need for and demand health care and the professionals themselves should encourage other health workers to deal with children with disabilities in an accepting and understanding manner.

Optimising the management of the intercurrent illnesses these children are prone to probably demands a judicious mix of the above two approaches depending on local resources and recognising the impediments that tend to occur. At present, for the majority of centres the first of the two approaches is not yet an option.

These centres illustrate the premise, expressed in the motivation for the study, that health services depend on history and personal contact. Two neighbouring centres have completely different approaches to management of intercurrent illness. At one centre a member of staff takes children to a specific doctor at a Day Hospital which is round the corner. The other, in all cases, asks the parents to take the children to a doctor. In the latter case, the contact has not been made although 200 metres away a smooth system is working. One centre in a deprived area can count on a G.P. for all the children's needs while 8 others are hamstrung if a child has a non-urgent intercurrent illness and the parents do not follow the staff's advice. Proximity to health facilities works for one centre which, being on the grounds of a general hospital, can use its facilities, and does not for another which, although occupying a hospital building, has no direct communication with hospital medical staff. These instances illustrate the uncoordinated nature of services to the centres.

6.7.2 Urgent

Acute and emergency health problems are a fact of life for those who care for children. They are not common but demand prompt attention. All of the centres bar one were able to identify a health facility to which an ill child could be taken. Examples of problems for which this has become necessary were prolonged seizures and fractures. Most centres used the local Day Hospital although one centre reported that the Day Hospital refused to see the children, maintaining that their problems were too specialised. This results in a 25km journey to Red Cross War Memorial Children' Hospital for acute problems! Local G.P.s play an important part in being available for emergencies, serving 8 centres, 3 of them afterhours. G.P.s make themselves available to come in an emergency to 7 centres, and 2 centres on the grounds of general hospitals can call in a doctor from the hospital. These are resources that could be built on. That 50% of the residential centres have no doctor on whom to call is unsatisfactory.

The American Academy of Pediatrics recommends training of staff, especially the nurse, in emergency care with a kit being kept at the school. A useful element for centres such as those under discussion is a solution of diazepam for rectal use to control seizures. The school should have a doctor who could come if available (Committee on School Health, 1990).

The lack of someone to call upon, which is the lot of the staff of 73% of the centres, is a cause for concern. Most of these centres do not have a nurse either, leaving the teaching staff responsible. The degree of competence of the staff in dealing with these emergencies is not known but some of the Heads interviewed do not relish the responsibility. Whether centres have First Aid kits was not studied.

A coordinated system of cover is probably practicable considering that some of the centres have managed to make local contacts, but help from other authorities is likely to be essential considering the disparate nature of the centres. The object should be to enable centre staff to deal with common emergencies (especially seizures) with back-up from medical professionals and facilities.

The data has shown that in one third of cases the centre sends a teacher with a child who has to attend a health facility. This probably reflects a lack of choice of staff members as the time spent away from the centre detracts from the education of other children. Measures such as preferential consultation at the hospital would reduce this waste of valuable time should there be no other person to accompany the child. The nurse is the other staff member mainly responsible for accompanying children. Were health facilities to be more expeditious in their handling of children known to come from these centres, the nurse would feel freer to send other staff members with the children. Many nurses felt that, at present, their presence is necessary to reduce delays at hospitals. Clearly, a nurse should accompany a child if there is an emergency situation.

6.8 SATISFACTION OF INTERVIEWEES

With fewer than a quarter (8 out of 33) of the interviewees expressing satisfaction with the services the centres encounter, clearly much needs to be done. Nurses tended to be more content (35%) than the heads interviewed (17%). This may be a function of the greater medical input at the centres with nurses although, conversely, one might expect nurses to have greater insight into any deficiencies in a medical service.

As has been shown, the Special Care Centres receive the worst cover and only 2 of them (the 2 residential ones) were satisfied. Half of them were unequivocally dissatisfied. Thus, where services are worst, this is recognised. Satisfaction with a service is a function of expectations of that service in a given context. It is important to note that satisfaction was expressed where children were only seen once during their schooling and where no regular reviews took place suggesting that regular assessment of children with disabilities was not important. This may reflect the populations being dealt with, the nurses' confidence or a background of medical input not reflected by the study. Supporting the first of these postulates is the finding that in none of the centres for white children was the interviewee less than "mostly" satisfied, a degree of complacence not demonstrated by the other groups.

The wide variety of suggested improvements to the service indicates diverse reasons for dissatisfaction. The most prevalent wish was for medical input where there was none or greater involvement where there was. Generally the theme was the need for a greater service in many areas to and in the centres. This wish for greater medical involvement at the centres accords with the literature cited in the discussion of the various professionals involved in the care of children with disabilities in Sections 6.3,4 and 5, and is an encouraging point from which to make recommendations.

CHAPTER SEVEN

CONCLUSIONS

In view of the many health professionals and health facilities involved in the care of children in centres for the physically and intellectually disabled, there is an urgent need for coordination. This is highlighted in the study by, for example, the poor communication between the centres and hospitals.

Coordination of services is discussed by Aiken *et al.* (1975). They describe 3 aspects to coordination:

i. Comprehensiveness
   - all necessary resources and services are in fact present and available

ii. Compatability
   - there is coherent linking and sequencing of elements

iii. Cooperation
   - the relationship between the various components of the system

The elements requiring coordination in the area of human services are:

- programmes and services
- resources
- client or patient access
- information
- relationship between elements

and within each of these areas there should be comprehensiveness, compatability and cooperation.

Aiken *et al.* discuss a number of service systems for the intellectually disabled in the light of these factors and point to how, where they were inadequately addressed, services failed to achieve their objectives. They propose a 3-tiered structure in which the lowest is the organisation responsible for case coordination; the middle, a coalition of organisations responsible mainly for ensuring comprehensiveness of services; and the highest, the community board, provides political support and public accountability. An alternative suggested is the creation of a single organisation that does nothing but case coordination and thus is not directly involved in service delivery as, they argue, this always produces a conflict of interests that limits proper coordination.

Lack of coordination produces duplication, omissions, wasted resources, incomplete information and communication and inhibits progress and power for the organisations involved.

For children with developmental disabilities the elements which need to be coordinated to produce a comprehensive service are:

- education, including
  - career advice
  - planning appropriate placement
- health services, including
  - initial assessment
  - ongoing reevaluation
  - rehabilitation
  - emergency care
  - continuous medical therapy
  - paramedical input
  - health education
  - mental health intervention
  - subspecialty intervention including genetic advice
- social support, including
  - welfare organisations
  - support groups (eg. Down's Syndrome Association)
  - information about services

- acquisition of aids and equipment
- respite care
- support for the family

The present system of service delivery to children in centres for the disabled does not warrant the term "system" as it is largely a series of ad hoc arrangements cobbled together by multiple individuals and organisations. Regarding health care, no coordinated plan exists. Rather it is each centre for itself demonstrating the veracity of the original premise of the study that services are largely a result of personal contact and history.

The reasons for this are not hard to find and are not unique to people with disabilities. The health service itself is fragmented with many different health departments depending on race and tribe and with preventive and curative services separated. Services to whites have tended to be well funded and complete and to blacks and "coloured" people limited and often rudimentary (Seedat, 1984). For children with disabilities this study has shown that even whites do not receive comprehensive health care which is well coordinated. Even the centres which declared themselves satisfied with services did not ensure comprehensive care for all the children.

If one analyses the problems in terms of Aiken's 3 components, comprehensiveness of resources is probably present, although at present scattered and disjointed. Medical, nursing and dental expertise and manpower are available though numbers may not be adequate, assuming willingness. Compatability is hamstrung by fragmentation and there is no mandated sequence of health care for disabled children. For example, many children are in centres having never had a full assessment (V. Mahlati, - personal communication). Cooperation is gamely managed for some centres by the nurses but is a hit-and-miss affair as the role of the centre in health care is not clear. This is the crux of the matter. Until the role of the centre in health care is clarified services will remain disjointed and partial (in both senses of the word).

CHAPTER EIGHT

RECOMMENDATIONS

In formulating recommendations, the last point of the preceding section (that the role of the centres in health care needs to be clarified) is central and, if this point is not addressed, recommmendations have no context in which to have meaning. One cannot make specific recommendations as each centre is different and yet general recommendations have little chance of implementation as there exists no structure through which this could be done. General recommendations would have to be so broad as to be unhelpful.

The paramount need is for a clear role for the centres in comprehensive health care and this is the key to providing a coordinated, comprehensive service for the children. To this end the following are recommended:

i. There must be a unitary health system and a single education department in the country.

ii. The present health care role of centres for children with disabilities should be acknowledged by the educational and health authorities.

Societies and associations for the disabled as well as parent groups should use such information as that contained in this study to lobby

a) <u>health service providers</u> to improve the provision of services to and in the centres. Health departments include the Department of National Health and Population Development, Hospital Services (C.P.A.), Day Hospital organisations, academic departments, General Practitioner groups, the Private Paediatricians group and local authority departments.

The aim of this pressure is to:

- convince the authorities of the value of input into the centres;
- regularise visits by doctors;
- provide health care at every centre from its inception;
- provide paramedical staff;
- encourage acknowledgement of the special needs of children with disabilities;
- provide appropriate equipment for examination and rehabilitation, and
- encourage training of personnel.

b) <u>education departments</u> to:

- acknowledge the benefit of the medical role in the schools;
- allocate space for health-related activities, and
- recommend and contribute to annual reviews for all children.

The societies themselves should:

- allocate space in their centres for medical and counselling activities;
- cooperate in pursuit of adequate medical services for their centres.

iii. The centres should take a central role in coordinating care of the children. The advantages of this were discussed in Section 6.3.

In order for this to be efficient and effective there needs to be:

Cooperation

<u>Medical Staff</u>:

Communication between hospital and community staff should be improved (eg. through use of referral forms that accompany the child, copies of inpatient summaries being sent to the school on discharge) and would be if the centre were the coordinating point; the role of each doctor involved in child care should be clarified;

Nursing Staff:

School Nurses should establish links between themselves for support and service reasons. Links with general School Health Services should be sought;

Dental Staff:

The relationship between Oral Hygienists visiting the centres and Dentist or Dental Clinic should be clarified by the clinics involved;

Centres:

Existing links between centres (such as the Western Cape Forum for Mental Handicap) should foster further links with other centres to work for and monitor medical services in the centres. It is strongly recommended that staff from centres in the same locality cooperate to make most effective use of the services in their area. Much could be done while awaiting coordinated management from health and education departments.

Compatability

Medical services:

Making the centre the coordinating site for each child's care, as recommended above should markedly promote interlinking and streamlining of services;

Nursing services:

The nurse should be the key person ensuring that all elements needed for the child's care are working in concert and she should be supported in this function;

Dental services:

The steps necessary for administration of general anaesthetic need to be steamlined for children with severe disabilities; services geared to children with special needs should be available on a wider basis.

Training

Medical Staff:

Doctors in private and public community settings should be recruited and given supportive training in the management of children with disabilities to establish sympathetic and continuous care. This could be done by staff from Specialist services such as Neurology and Cerebral Palsy clinics through attachments and seminars. Active support of the controlling body would be important;

Nursing Staff:

Nurses in centres should receive in-service training in Paediatric Primary Care and be able to use these skills. A priority is to ensure that the nurses are able to screen vision and hearing. Skills in case management should also be taught. This could be achieved through in-service training already given to other School Health Nurses, Paediatric Primary Health Care courses given at the Red Cross War Memorial Children's Hospital, and courses run by academic nursing colleges.

Dental Staff:

Existing educational strategies should be evaluated to produce optimal understanding of the needs of people with disabilities which will promote greater willingness and ability to serve them.

Research

While this study has provided some information on health services for children with disabilities, there are many areas and aspects which it would be useful to elucidate while attempting to improve the services. It would be valuable to know:

- how the doctors view the service they give and where they feel improvements might be made;

- how many children from other centres are reviewed at general and day hospitals and how comprehensive these reviews are;

- how many children are seen by private practitioners and what role they play;

- parents' views on the role of the centre in their children's health care.

There are many other areas worthy of study (eg. the teacher's role in the children's care) but the above would be crucial in service planning.

Academic Departments

The role of academic departments in services to the centres needs to be singled out. Present interest should be capitalised upon to map out an expanded involvement in this area. The most useful input these departments can have is in setting up and evaluating models of health services to children in the centres. Academic departments should also take on some of the training and research necessary for effective and efficient provision of comprehensive services.

Finally, there are reasons for contemplating an even greater role for the centres. It was shown earlier (Chapter 1, p8) that in some sectors these centres cater for a relatively small number of children with significant disabilities. Community resources are generally not geared for such children as this study has shown and yet these centres have a range and depth of expertise and have staff committed to the welfare of children with special needs and are by and large located in community settings. Could these centres not serve as a resource of training, information and certain services to those situated beyond their walls? The concept is not unique (Miles, 1990) and has the potential to serve as an appropriate way to address the needs of all children with disabilities and their families.

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APPENDIX 1

Date / /

SECTION 1

NAME OF CENTRE:
Centre No. #

a) Number of children in centre:
b) Age range of children:
c) Type of centre:

Special Care	Res	1
	Nonres	2
Training Centre	Res	3
	Nonres	4
School Physically Handicapped	Res	5
	Nonres	6
Training C Physically Handicapped	Res	7
	Nonres	8

d) Main funding of Centre:

Self Supporting	1
NGO	2
Government Department	3

e) Population Group:
f) Name of senior Nursing Officer:
g) Name of interviewee (when not Nurse):
h) How long employed at centre:

SECTION 2

QUESTION ONE
How many nurses work at the centre? #

QUESTION TWO
What are their qualifications and what courses have they done?

1 2 3

QUESTION THREE
How long have they worked with disabled children?

1 2 3

SECTION 3

QUESTION ONE
Do you have a doctor who comes to see the children in your centre ?

YES / NO
1 2

If yes: (Question 1.A) *If no*: (Question Two)

1.A) How many doctors visit regularly? #

(Names)

1.B) Is/are the doctor(s)

		Number	Origin
Local GP	1	#	______
District Surgeon	2	#	______
Spec. Paed.	3	#	______
Spec. Neur.	4	#	______
MO from local health centre	5	#	______
Geneticist	6	#	______
Orthopaed. Surgeon	7	#	______
Other Medical Officer	8	#	______
Ophthalmologist	9	#	______
ENT Surgeon	10	#	______
Neurosurgeon	11	#	______

Comments:

1.C) How often do you have a doctor on the premises seeing children?

Every day	1
2-4 days/week	2
Weekly	3
Monthly	4
3 monthly	5
6 monthly	6
Yearly	7

Comments:

1.D) Which children are seen by these doctors?

All children once a year	1
All children at some time	2
New children	3
Only those with problems	4
Particular ages	5
Particular standards	6

Comments:

1.E) Are any of the doctors paid for the visits:

By the centre	1
By controlling body	2
By other authority	3
Don't know	4
Not paid	5

Comments:

QUESTION TWO

Do you have arrangements for the children to be regularly seen elsewhere?

YES / NO
1 2

If yes:

2.A) Where?

Day Hospital	1
G.P.	2
Gen. Hosp OPD	3
Gen. Hosp Spec. Clinic	4
Local Authority Clinic	5
Other	6

2.B) How often? ______________________

2.C) Are they seen by

Medical Officer	1
G.P.	2
Spec. Paed.	3
Spec. Neur.	4
Geneticist	5
Registrar	6
PHC Nurse	7
Other Nurse	8
Other (Specify)____________________	9
Don't know	10

Comments:

2.D) Are any of the doctors paid for the visits:

By the centre	1
By controlling body	2
By other authority	3
Don't know	4
Not paid	5

If no:

2.E) If a child is having problems related to the handicap how do you get him/her seen by a doctor?

Take the child to:

Day Hospital	1
G.P.	2
Gen. Hosp OPD	3
Gen. Hosp Spec clinic	4
Other	5
Ask parents to take child to their own doctor	6
Have to ask parents to take child to a doctor	7

Comments:

QUESTION THREE

For non-urgent medical problems unrelated to the child's handicap, to whom do you refer?

Day Hospital	1
G.P.	2
Gen. Hosp OPD	3
Gen. Hosp Spec clinic	4
Vis. Dr on premises	5
Other	6
Ask parents to take child to their own doctor	7
Have to ask parents to take child toa doctor	8

Comments:

QUESTION FOUR

If you need an urgent medical opinion, is there a doctor who will come to see the child at the centre?

YES	NO	SOMETIMES
1	2	3

If YES:A Is it

One of the visiting Drs	1
Local G.P	2
Dr from Day Hospital	3
District Surgeon	4
Other	5

If NO or if unavailable:

A) Where do you refer?

i) during weekdays

Day Hospital	1
G.P.	2
Gen. Hosp OPD	3
Gen. Hosp Spec clinic	4
Other	5
Ask parents to take child to a doctor	6

ii) at weekends

24hr Day Hospital	1
Gen. Hosp.	2
Not relevant	3
Other	4

iii) at night

24hr Day Hospital	1
Gen. Hosp.	2
Not relevant	3
Other	4

Comments:

QUESTION FIVE

5.A) Who usually takes the children to the health facility?

Nurse	1
Teacher	2
Housemother	3
Nurse aid	4
Gen assistant	5
Other	6

(Specify):____________________

5.B) Are any problems experienced in using these health facilities? Please explain.

QUESTION SIX

Does a dentist visit the centre?

YES / NO
1 2

If YES:

A) How often?

Monthly	1
3-monthly	2
6-monthly	3
Yearly	4
< once a year	5

B) Is he/she

Government dentist	1
Private dentist	2

C) Is he/she paid for the visit?

YES / NO
1 2

If NO:

D) Do the children pay a regular visit to the dentist?

YES / NO
1 2

If YES:

E) Where?

Day Hosp	1
Dental Clin	2
Private Dent.	3
Other	4

E) How often?

Monthly	1
3-monthly	2
6-monthly	3
Yearly	4
< once a year	5

Comments:

QUESTION SEVEN

Does a nurse visit the centre?

YES / NO
1 2

IF YES:

7.A) Where does she come from?

Local authority clinic	1
School health service	2
Day Hospital	3
Volunteer	4
Non-governmental organisation	5
Other	6
(Specify): ____________________	

7.B) How often does she visit?

Monthly	1
Quarterly	2
6-monthly	3
Yearly	4

Comments:

QUESTION EIGHT

Is the present situation regarding medical and dental cover for your centre/school satisfactory?

Yes	1
Mostly	2
Partly	3
No	4

Comments:

QUESTION NINE

What for you would be the 3 most useful improvements to medical or dental cover that could be made?

1. ______________________________
____
____

2. ______________________________
____
____

3. ______________________________
____
____

APPENDIX 2

PROMPTS AND EXPLANATIONS

The following are the allowed prompts and explanations to be used as needed during the administration of the questionnaire (Appendix 1). Also included are explanatory notes regarding the administration of the questionnaire. These are given in the order in which they appear in the questionnaire (Appendix 1).

SECTION 1

a) The number of children actually registered with the centre.

b) The age range of children usually accepted into the centre.

c) See under "Definition of Terms" in main document. "Res" is recorded if part or all of the centre is residential.

g) This is to be asked at the end of the interview except if the nurse is the interviewee when Section 2 will apply.

SECTION 3

QUESTION ONE

if Yes:

1.B) Ask for numbers and names. (See "Ethics" section of main document) Organisational source to be filled under "Origin" if known by interviewee.

D) Ask Head of the centre if the Nurse does not know.

Interviewee may answer more than one if there are many doctors.

QUESTION TWO

If "regularly" is not understood the interviewer can explain its meaning. If the interviewee is uncertain this will be recorded as "no".

if Yes:

2.C) Record names if needed.

2.D) As for D above.

2.E) "Handicap" is used to improve understanding. "Impairment" is a more accurate word in this context. The interviewer will give examples appropriate to the type of centre eg. fits, behaviour problems. Because there may be differing arrangements for different children, 2 answers may be recorded. Hospital names will be taken to help in coding if there is doubt as to their nature.

QUESTION THREE

As for E) immediately above.

QUESTION FOUR

ii) and iii) are not relevant for Day Centres and will be coded accordingly. Any "Other" sites of referral will be recorded.

QUESTION FIVE

Problems experienced will be recorded verbatim or in point form.

QUESTION SIX

If No:A) "No" to include "uncertain".

QUESTION EIGHT

All four options will be given and one chosen.

QUESTION NINE

Answers will be recorded verbatim as far as possible.

APPENDIX 3

SPECIAL CARE CENTRES

De Heide Children's Care Centre,41 Jonkershoek Rd.,Heideveld

Etembeni Special Care Centre,C/o Cape Mental Health Society,P.Bag X7,Observatory

Friends Day Centre,P.O. Box 229,Maitland

Glendale Special Care Centre, Galway Rd.,Heathfield

Imizamo Yethu Centre,C/o Cape Mental Health Society,P.Bag X7,Observatory

Mitchell's Plain Special Care Day Centre,C/o Cape Mental Health Society,P.Bag X7,Observatory

Oasis Special Care Centre,cnr Christiaans and Northway Streets,Ravensmead

Ocean View Special Care Centre,cnr Castor and Draco Ways,Ocean View

Sherwood Park Centre,4th Avenue,Sherwood Park

Siyazama Day Centre,C/o Ms V Muhlati,OT School,UWC,Modderdam Rd, Bellville South

Sunrise Special Care Centre,C/o Mrs P Kammies, Oribi Ave,Lotus River

Woodside Sanctuary,27 Lawson Rd.,Rondebosch East

TRAINING CENTRES (mentally handicapped only)

Alta Du Toit Centre,Lincoln St.,Bellville

Beacon Training Centre,P.O. Box 346, Mitchell's Plain

Bel-Porto Centre,P Bag X3, Clarinch

Blouvlei Training.Centre,P.O.Box 124, Retreat

Chere Botha Centre,73 Van der Stel St.,Oakdale,Bellville

Gerard's Educare and Down Syndrome Centre,cnr Cayen and Strandfontein Rds., Strandfontein

Glendale School for Specialised Education,Galway Rd.,Heathfield

Lentegeur State Training Centre,Lentegeur Psychiatric Hospital,Lentegeur, Mitchell's Plain

Mary Harding Centre,Klipfontein Rd.,Athlone

Molenbeek Training Centre,Alexandra Care and Rehabilitation Centre,Maitland

Nompumelelo Training Centre, NY5, Guguletu

Oasis Training Centre,Old Stellenbosch Rd.,Clarke's Estate,Elsie's River

*Ocean View Training Centre,*cnr Castor and Draco Ways, Ocean View

*Peter Pan Preschool Centre,*101 Hope St.,Cape Town

TRAINING CENTRES (physically handicapped)

Bluegum Training Centre, Tarentaal Rd.,Bridgetown,Athlone

*Heideveld Training Centre,*Tarentaal Rd., Bridgetown, Athlone

SPECIAL SCHOOLS

*Agape School,*Yellowwood Rd.,Tafelsig,Mitchell's Plain

*Astra School,*Pallotti Rd,Montana

*Eros Cerebral Palsy School,*Tarentaal Rd.,Bridgetown, Athlone

*Paarl School,*Rogland St., Brackenfell

*Tembeletu School,*NY3 Guguletu

*Vista Nova Cerebral Palsy School,*11 Milner Rd., Rondebosch

APPENDIX 4

«DATA a:address2.txt»

«addressee»
«addfirstl»
«addsecl»
«addthirdl»
«addfourl»

August 1991

Dear «name»,

I am a doctor working at Day Hospitals and the Developmental Clinic at the Red Cross War Memorial Children's Hospital. I have also worked at the Neurology Clinic at the hospital. This has brought me into contact with the children from many centres and schools for the physically and mentally handicapped. As you will be well aware these children often have many and recurrent problems requiring a doctor's opinion. I noted that staff and parents often had difficulty gaining access to a doctor who understood their special needs and , in order to document this impression, I am planning a research project under the auspices of the Child Health Unit of the University of Cape Town. I would hope that the information gained would help in plugging gaps and perhaps establishing a system of medical help for these children.

To this end I would be grateful if I could visit your school and interview you or the school's nurse in an effort to find out how a medical opinion is obtained for children at the school.

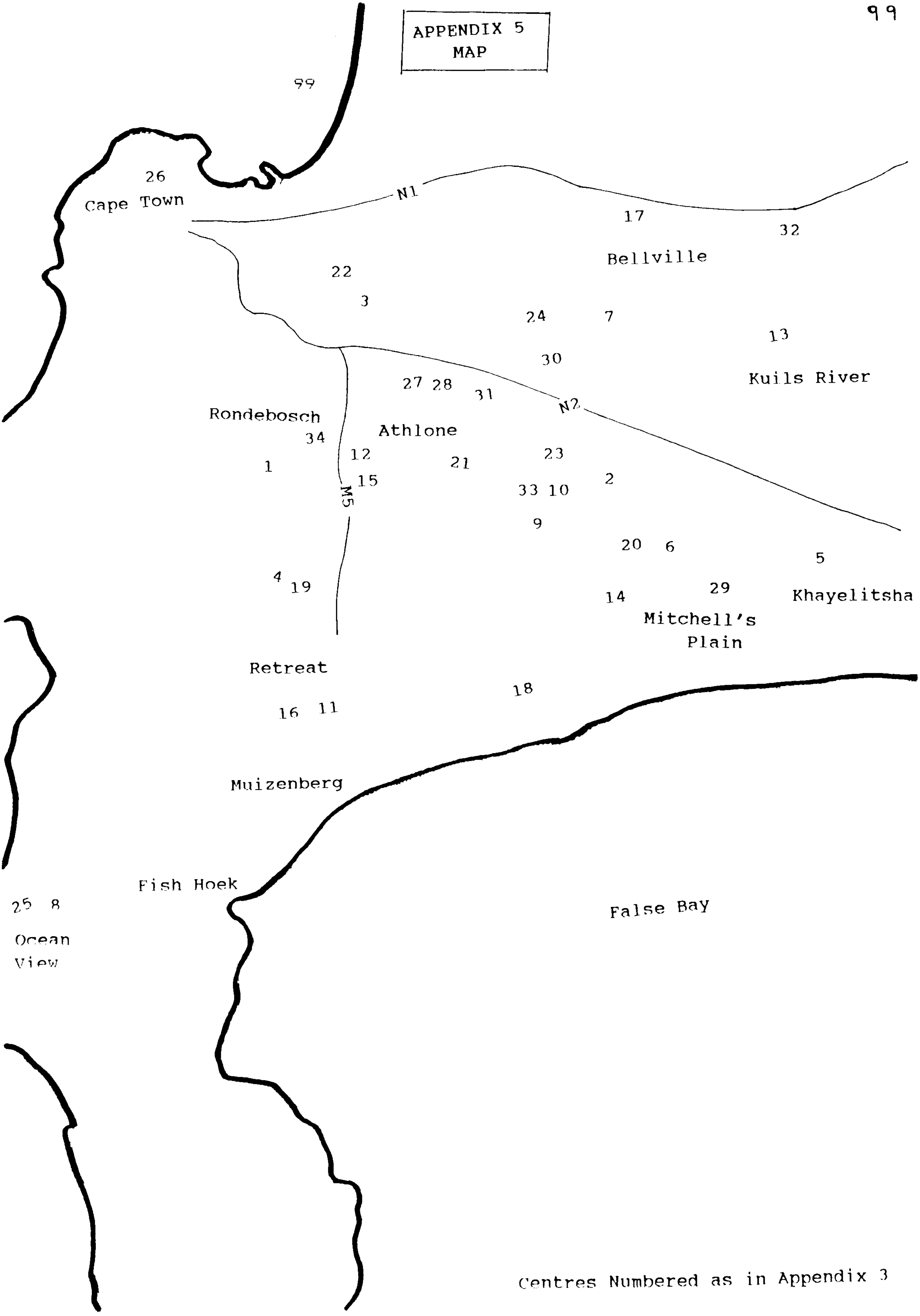
I plan to do the research in September and October this year and will phone your school closer to the time to introduce myself (if I have not already met you) and make an appointment for the interview.

If I need permission from a higher authority to conduct this research at your school, please would you contact me at Tel. 6854103 ext. 269. I look forward to meeting you and learning something of your joys and difficulties in caring for a special and needy group of children.

Yours sincerely,

DR. A.T.R. WESTWOOD

APPENDIX 5
MAP



Centres Numbered as in Appendix 3