IDENTIFYING DISABILITIES IN CHILDREN ~~IN DEVELOPING COUNTRIES~~ BY MEANS OF A BRIEF 'OBSERVATION OF FUNCTION' FOR USE IN DEVELOPING COUNTRIES.

A thesis submitted to the University of London for the degree of Doctor of Philosophy in the Faculty of Science

By

NAILA. Z. KHAN

The Wolfson Centre

Department of Neurology and Developmental Paediatrics

Institute of Child Health

October 1991

ABSTRACT

This study was an offshoot of a collaborative survey called the 'Rapid Epidemiological Assessment of Childhood Disabilities' (REA) undertaken in three developing countries, Bangladesh, Jamaica and Pakistan, aiming to develop a screening procedure for two-to-nine year old children for disabilities of movement, hearing, vision, speech, cognition and epilepsy.

To facilitate physicians doing comprehensive neurodevelopmental assessments of large numbers of children within the community, this study aimed to verify whether a brief procedure of observing children perform a simple set of tasks, called the 'Observation of Function' (OF), could identify disability validly and reliably (first part of the study). Subsequently, the OF was used by community workers (CWs) doing field work, to verify whether they too could use it validly and reliably (second part of the study).

The analysis of the first part was done on 1626 children from five sites in Bangladesh, who had either been screened positive by the REA study or assessed as controls. Over half of the total number of disabilities were identified by the procedure, including most serious problems. It did best for motor disabilities; hearing and vision were the least identified, especially isolated problems. Significantly more younger children were identified.

The yield of the OF was best when combined with the mother's history.

The CWs did not do as well with the procedure. Poor sensitivity in case identification was seen as an absence of 'internalized standards' of child development. However, some problems were identified consistently, as evidenced by the high reliability scores, suggesting future potential for improving the capacity of the CWs for using the OF.

Thus this study suggests that the OF can be a valuable neuroepidemiological tool to be used by physicians during field work. It may also aid them in busy clinical settings to focus on function-specific evaluation. The value of involving CWs in the screening as well as the evaluatory (OF) stage of identifying childhood disabilities in developing countries holds practical significance, and ways of improving their further training is discussed.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

ACKNOWLEDGEMENT

I am grateful to Prof. Kenneth Holt for supervising this thesis. I have gained much from his wisdom and experience. I thank him for his support throughout my studentship.

The Wolfson Centre (TWC) has been a defacto family to me. I am grateful to everyone there for helping to keep my spirits up. Prof. Brian Neville, despite the pressures of his new assignment as Director of TWC, has always shown keen interest in my work with disabled children in developing countries. I have learnt much about developmental paediatrics from Dr. Patricia Sonksen, which will not only be remembered but come to good use in my future work in Bangladesh. I am especially obliged to Dr. Anthony Ades from the Department of Epidemiology, Institute of Child Health, for helping me with the analysis.

To no person do I owe as much as I do to Dr. Helen McConackie without whom this thesis would not have matarialized. She has read, edited, given suggestions, and inspired me into finishing chapters.

I am most grateful to Drs. Sultana Zaman and Sultana Banu of the Psychology Department, Dhaka University and Drs. Zena Stein, Leslie Davidson and Maureen Durkin of the Sergievsky Center, Columbia University, New York, for encouraging me to do a thesis from work that we had all contributed in.

I thank Drs. Ejaz Rasul and Shameem Ferdous for their contribution in assessing children in the two parts of the study respectively. Sharmeen Habib, Shirin Munir and Ashoke Ray have been invaluable in doing the psychological assessments. I also thank John Martin D'Rozario for his help in computer programming. I remain indebted to my friend Shahadat Chowdhury, editor, The Weekly Bichitra for giving me access to their computer. Rezaul Hossain Reza has programmed the final formatting and printout of the thesis, for which I am grateful.

Padma Anagol needs separate mention for encouraging me in times of stress and for being a friend when I needed one most.

Finally, this thesis has been the outcome of a lot of sacrifice from my family in Dhaka, Bangladesh, to whom I remain ever-obliged. My husband, Shahidullah Khan, son Almer and daughter Aneire have spents months without me, always with smiling faces. I thank both my parents Dr. Sultana Zaman and Quazi Nuruzzaman for their support to all four of us, and especially to me in deciding to pursue higher studies abroad.

CHAPTER ONE

FUNCTIONAL EVALUATION OF CHILDREN FOR DISABILITY IN DEVELOPING COUNTRIES

Introduction

More than half of the world's children and three-fifths of all disabled children live in developing countries (WHO, 1981; Noble, 1981). Their survival through childhood and development into adulthood continues silently; most problems of health and/or disability remain unaccounted and undetected by formal health services (Walsh and Warren, 1979; Evans et al, 1981; Marfo, 1986) . There are several reasons for the lack of attention. The health care system is centralised, hospital-based, and physician orientated. The physician to population ratio is low, more so in rural areas where the majority of the population live. Where service is available, the focus is more on acute easily treatable conditions with high fatality (Walsh et al, 1979; Evans et al, 1981). Such an infrastructure precludes universal developmental monitoring and early identification of conditions with long-term implications for the health and abilities of children. Yet with growing commitments of health planners towards strengthening primary health care and an insidious but definite trend towards declining mortality rates, the need to identify children at risk of or having disability is increasing, for the sake of primary and secondary prevention, and rehabilitation (Marfo, 1986). Given the fragile infrastructure, simple and functional methods of case identification and evaluation are required to cover large populations and to make best use of limited resources and shortage of personel. As an off-shoot of an epidemiological study of childhood disabilities in Bangladesh, this study aimed to develop a procedure for identifying disabled children, aged two to nine years, within community settings, which would be simple, brief, and functional, for use by physicians doing comprehensive neurodevelopmental assessments. Standardisation of such a procedure will enable larger numbers of children to be assessed in much less time and in their own environment. The study also hoped to verify whether the same procedure could be used by community workers to identify disability, thus involving them in the evaluative process.

1.Child health and disability in developing countries:

The concept of health has undergone rapid changes within the past few decades. Development of such fields as medical anthropology, demography and epidemiology have demonstrated the socio-cultural, economic and environmental aspects of health and disease, making the possibility of disease prevention and control a realistic possibility for poorer nations. Whilst in practice the reliance on western-styled curative medicine continues, most governments today are committed to prevention and universal primary health care based on evidence that strongly favours such policies.

For example, a dramatic decline in infant mortality rates has been documented in recent times in developing countries with targeted programmes like that of Cuba or in specific locales such as Matlab in Bangladesh, and Soweto in South Africa (Diaz-Briquet, 1981; ICDDRB, Bangladesh, 1982; Herman and Wyndham, 1985). Attributable factors have been public health care measures such as programmes implementing the GOBI, FF[1] advocated by UNICEF (Grant, 1988) and changes in social factors such as maternal health and education (Saksena and Srinivasta, 1980; Bairagi, 1980; Fauveau et al, 1990). As a result, child survival has become an important indicator of the quality of primary health care and socio-economic development (Stein and Susser, 1980). The tempo and pattern of changes have been much more dramatic than those that occurred in Europe at the turn of the twentieth century, where survival had already been improving in older children and young adults for a full five decades (Reves, 1985; Susser et al, 1985). The differences in demographic dynamics makes the situation evolving in developing countries unique; a situation whose implications cannot be read from the experiences of developed countries, but needs to be studied.

Child survival has also been shown to have significant effects on the acceptability of other programs such as familiy planning, a programme that commands high priority in most developing countries. Studies in Bangladesh show that an infant death reduces the average

---

[1 GOBI, FF is an acronym which stands for growth monitoring, oral rehydration,breastfeeding, immunisation, family planning and food.]

interval between births from more than three years to less than two (Grant, 1991).

Child survival per se loses meaning without a qualitative appraisal of life. Therefore, it is no longer sufficient to state the number of children surviving infancy and childhood. This was especially recognised by world bodies and individual governments during the International Year of the Child (IYC) in 1979 and the Internation Year of Disabled Persons (IYDP) in 1981. It was becoming evident that more qualitative aspects of survival were required to be measured; aspects that realised and exploited the full potential of children to develop into productive adults within their respective communities. The frequency and distribution of childhood disabilities was stressed as one such important measure (Hammerman and Maikowski, 1981). Epidemiological studies were initiated in several developing countries to see its extent and relative distribution (Hammerman, 1984).

The following conclusions were generated from these studies. Firstly, it was estimated that over 70% of the world's disabled people live in developing countries (Noble, 1981). World Health Organization (WHO) estimates pointed to a 15-20% disability rate (WHO, 1980a). The United Nations Childrens Fund (UNICEF) estimated that by 2000 a.d. there would be more than 150 million disabled children under the age of 15 living in these countries (Noble, 1981). Secondly, it was established that most of the causes of disabilities, like the more generalised causes of high mortality, were due to preventable conditions (Hammerman, 1984; Marfo, 1986). Malnutrition, infections - viral, parasitic, or bacterial - and communicable as well as noncommunicable somatic diseases were responsible for well over 50% of disability cases; genetic disorders accounted for less than 10%. Thirdly, simpler and more cost-effective methods of screening, assessment and rehabilitation were required, if the needs of the vast numbers of disabled persons were to be met universally (Belmont, 1984).

The overall disability rate and the questions about which persons and grades of disability to identify and rehabilitate have remained unresolved. The oft-quoted slogan '1 in 10 disabled' by the WHO and other agencies has been seen as an over-estimate in the light of studies in Asia where disability rates of 2-4% have been consistently reported by their families and neighbours

(Mia et al, 1979; Periquet, 1984; Narasimhan and Mukherjee, 1986). One reason for these lower figures might be that mildly impaired and disabled persons in these countries tend to be integrated into society without the label and stigma of disability, and when 'head counts' are taken they are not included. Only those with appreciable, noticeable disability of a sort that is not expected for the individual's age, are perceived as problems and reported. Therefore any kind of intervention would have to be directed more towards serious 'percieved' problems, and also towards milder problems that have not yet been identified by local communities but might benefit most from intervention.

Directly or indirectly, the IYC and the IYDP initiated interest within individual countries too. Efforts to collect information about some specific problems have been made locally by both governmental and non-governmental organisations, in collaboration with international agencies.

2. Studies on the extent of childhood disabilities:

Most information on childhood disabilities in developing countries have been generated from surveys on public heatlh problems of which disability is an outcome, the information about disability generated being related to the causal factor under study. For example, there is enough evidence about the extent of nutritional blindness caused by Vitamin A deficiency in Asia and Africa (Menon and Vijayaraghavan, 1980; Sommer et al, 1981; Cohen et al, 1986; Foster and Sommer, 1986). Studies have confirmed that poliomyelitis is a major cause of lameness in many of these countries (Expanded programme on immunization, Egypt, 1977; Ofusu-amaah et al, 1977; Soewarso, 1978; Ulfah et al, 1981). Other disabling conditions about which well-documented data exists are related to otitis media and deafness (Holborow, 1981), effects of malnutrition and psychosocial deprivation on mental functions (Cravioto and Robles, 1965; Monckberg, 1968; Richardson et al, 1973; Townsend et al, 1982), the effects of iodine deficiency disorders (IDD) on peri- and post-natal development (Ramalingaswami, 1961; Delange et al, 1972; Hetzel, 1983; Pharoah et al, 1984), and the neurological sequelae of intracranial infections such as meningitis, encephalitis and cerebral malaria (Schmutzhard and

Gerstenbrand, 1984; Phillips and Solomon, 1990). Most studies and consequent interventions programmes have been 'vertical' (Balasubrahmanyam, 1991) set against a background of unrealistic expectations and minimum professional interest, and failing to view child health and morbidity against the social, cultural, economic and political backdrop.

In Bangladesh, two major surveys were undertaken in the Eighties. The first, conducted on school-age children, revealed that while the entire country was endemic (ie. present in 10% of population) for nutritional goitre, large areas in the northern parts were hyperendemic (ie. present in over 30% of population) (Haque, 1984). The other known effects of iodine deficiency disorders, ie. variations of neurological or myxedematous cretinism (Delange, 1972), were not looked for. Another survey revealed the high prevalence of Vitamin A deficiency in children under five, with an estimated 25,000 going blind each year (Cohen, 1985; Helen Keller International, 1985). An earlier study, conducted during the IYC, had revealed the high prevalence of lameness attributed to poliomyelitis in the sample population (Mia, Islam and Ali, 1979).

Such evidence of increased morbidity related to nutritional and infectious problems have resulted in several positive primary health care programmes, such as the Expanded Programme for Immunization (WHO, 1979a; Expanded Programme for Immunization, 1987), distribution of high potency Vitamin A capsules (West and Sommer, 1987) and the iodisation of table salt (De Mayer et al, 1979). However, the selective and vertical nature of the programmes are evident, with no assurance of continuity. Doubts have emerged about advocating such programmes as 'magic bullets' or the panacea to child health problems (Vijayaraghavan et al, 1990; Balasubrahmanyan, 1991). On the other hand, socio- cultural and economic factors such as parental awareness and access to information, parental (especially maternal) education, dietary and food preparation habits, and the general level and coverage of primary health care have been found to effect morbidity that far outweigh any specific measure undertaken (Belcher et al, 1978; Bachani et al, 1983; Tsou et al, 1983; Bhuiyan et al, 1987; Fauveau, 1990).

Moreover, the quality of child survival is not insured by vertical intervention programs. A

pertinent point might be that disability has not been looked for as a unitary phenomenon, that encompasses the overall functioning of the child (as opposed to the involvement of a single organ such as the eye or ear or limb) and may involve more than one developmental domain. As a result no clear guidelines for programmes for the disabled have been drawn up regarding prevention, treatment or rehabilitation. This has lead to a failure in establishing the social aspects and future of the disabled child in each community.

3. Services for the disabled child:

Services for the disabled in developing countries are limited. Most services that have mushroomed over the last two decades are patchy and isolated from the primary health care and educational infrastructure.

In Bangladesh, the government has instituted provisions for the blind and the hearing impaired in mainstream schools as well as special schools. It also has two large centres for the physically handicapped, which act more as physical therapy centres rather than schools. Schools for the mentally handicapped are run by non-governmental organisations. Work is going on to develop more cost-effective methods of teaching activities of daily living and communication skills to disabled children in the rural areas through outreach programmes (Zaman, 1986). Though a commendable start, these efforts are negligible compared to the size of the population and the presumed extent of the problems.

A general review of the services for disabled children in other developing countries also reveals a similar scenario of selective services and heterogeneity of clientele. Amongst service providers there is an on-going conceptual debate about the correct way to proceed (Miles, 1986; O'Toole, 1990). Most existing services are in cities, are centre orientated and based on Western-style models of therapy and special education, reaching less than 2% of those in need (Moyes, 1981; WHO, 1982; Periquet, 1984). Community-based-rehabilitation (CBR) is excepted by most to be a much more realistic and acceptable option, utilising less trained personel, families and community members as the central service-providers. As a guideline for

CBR, the WHO has produced a series of manuals (Helander et al, 1983) that has been adapted for use in different countries.

Other informal programmes which can also be called CBR have developed. Exemplary ones are David Werner's work with the physically disabled in Mexico and his extensive compendium on childhood disaabilities (Werner, 1987), training of staff by the help of videos in doing home-based rehabilitation in Zimbabwe (McConkey, 1986; McConkey, 1988), dissemination of information on disability via radio programmes and information-based rehabilitation in Pakistan (Miles, 1985) and development of training programmes for persons working with the mentally retarded in Nepal (Gudalefsky, 1985).

Criticisms of the WHO-CBR programmes have emerged (Jaffer, 1985; Narasimhan and Mukherjee, 1986; O'Toole, 1987; Miles, 1990). While there is criticism of the role adopted by professionals which are inappropriate to the needs of their countries, there also seems to be an under-utilisation of available resources (Jobert, 1985; Djukanovic and Mach, 1975; Enwemeka, 1981). 'The low utilisation is especially apparent in certain sections of the community as a result of dissonance between the cultural orientation, values, and expectations of service providers and potential clients' (O'Toole, 1990). Such observations point to the need for a better understanding about the socio-cultural and economic aspects of disability on the one hand, and valid information about the extent of the problem on the other. Advocating CBR as a new programme to the dismissal of almost the entire present and previous efforts of families, neighbours, traditional healers, and local community resources has been noted (Leboyer, 1977; Boucebci, 1981; Miles, 1990). Instead of presenting any one approach on an *a priori* basis as the panacea to the problem (Wedell and Roberts, 1982), assumptions need to be tested before being adopted. They might work better if they fell within a conceptual framework encompassing all aspects of disability, acknowledging its relativity to communities within which it exists, and working within limited resources using cost - effective programs and appropriate technology.

4. Framework for planning programs for childhood disabilities:

It is evident that a model conceptual framework to address the problem of childhood disability does not exist in most developing countries. Most operative programs have been adopted on untested assumptions and on an empirical and adhoc basis. Based on experiences gathered in the past two decades, strategies for future work have been proposed. There is a general consensus that all programmes have to encompass the strategies of a) prevention b) screening or case identification c) evaluation and d) rehabilitation, incorporated within the primary health care infrastructure (Stein, 1990; Thorburn, 1990).

To aid in the above strategies, attempts have been made to develop more appropriate, locally derived methods of identification (Belmont, 1984), assessment (Baine, 1988; Serpell, 1988), and intervention (Helander et al, 1983; Werner, 1987). The standardisation of such methods is essential if they are to be advocated for use within large populations and for use by less trained personnel.

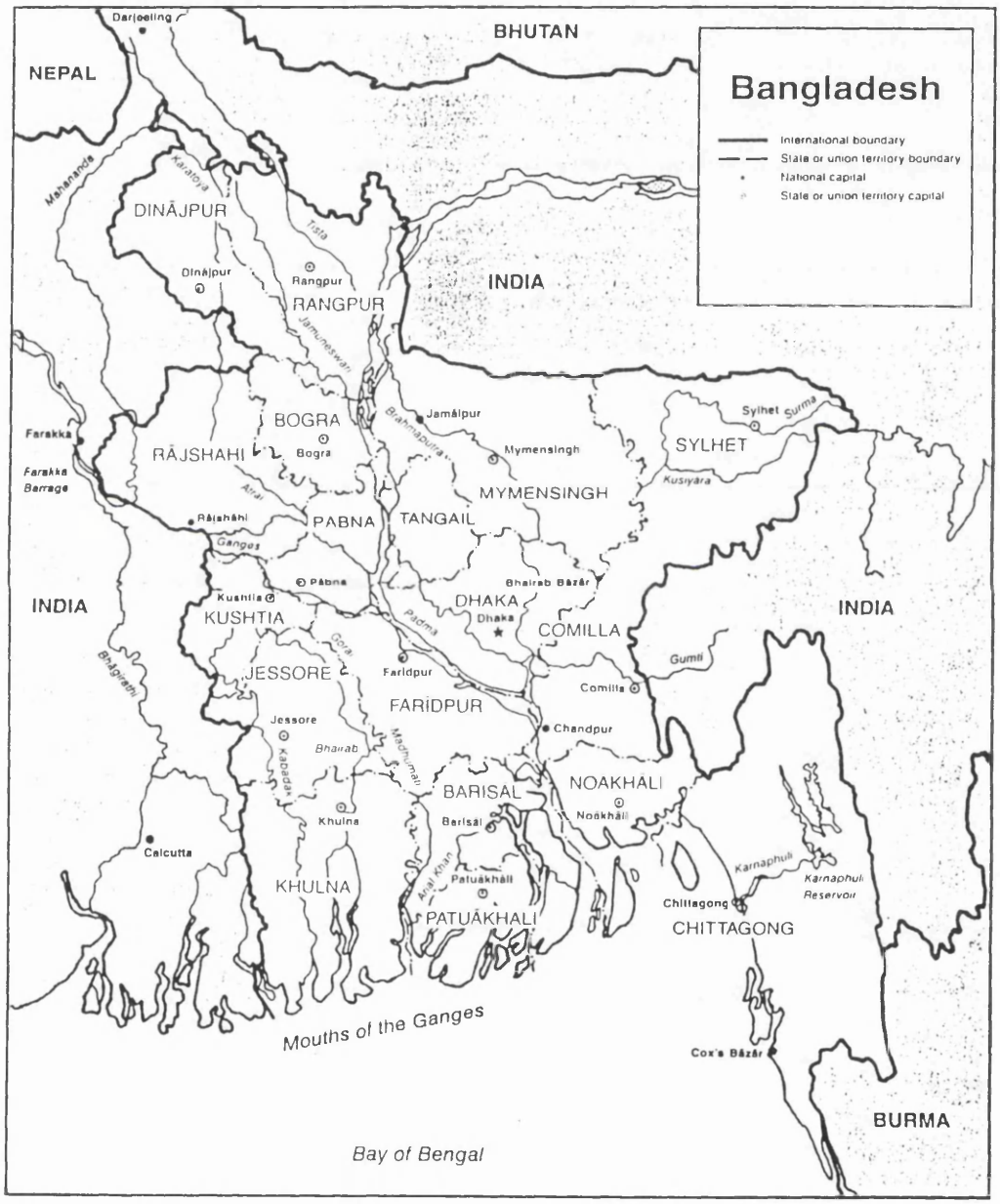
However, there are both universal as well as unique problems present in developing countries that severely restrict the quality of work required in standardising and developing such procedures via large-scale studies. Albeit these problems also apply in the the overall planning for early identification and rehabilitation and must be taken heed of if successes are to be achieved. Some of the more salient constraints are enumerated in the following section, within the unique situation in Bangladesh.

5. Constraints in studying childhood disabilities — the case of Bangladesh:

There are logistic constraints in carrying out large scale population based studies, that are endemic to most developing countries. These constraints also effect the implementation of programs. Limited resources, shortage of trained personel, poor communication, large populations and a fragile health infrastructure fall within this category. The disparity between planning and implementation of programs depend greatly on the extent of these constraints (Tarimo and Creese, 1990).

The following sections discuss the situation existing in Bangladesh, all of which justify

Fig.1.1 : The map of Bangladesh



the need for the development of decentralised, low-cost and simpler procedures for identifying children with disabilities within the community.

5.1. Difficult terrain :

Bangladesh is a fairly new country, having obtained its independance from Pakistan in 1971. It is part of the Indian Subcontinent, lies on the eastern-most parts of the peninsula (**Fig.1.1.**). The entire southern part is deltaic and coastal, opening into the Bay of Bengal. The climate is tropical, with summer and monsoon predominating.

The country occupies an area of 144,000 sq. kilometres. The terrain consists mostly of plains, except for the northern regions which have slight hills, extensions of the foothills of the Himalayas; these foothills also extend into the south-east and the area is tribal. Two large rivers, the Ganges and the Brahmaputra, flow into the country from the Himalayas, to empty into the Bay of Bengal. With the river Meghna, formed by the confluence of the Ganges and the Brahmaputra, and several hundred major and minor tributaries, it is a country whose every aspect of life is predominated by rivers (**Fig1.2.**). The billions of tons of silt brought by these rivers make Bangladesh one of the most fertile deltaic regions of the world. Paradoxically, these rivers are also the cause of massive floods during the monsoons in summer and the droughts during winter, attributed to several natural and man-made causes (Rogers et al, 1989). Droughts result in food shortage and high rates of childhood malnutrition in the lean seasons (Bairagi, 1980). Floods result in depletion of the soil of essential micronutrients like iodine, resulting in endemic goitre.

Rivers are the principal means of communication. The terrain is difficult and expensive for building roads, as many brigdes and culverts must be constructed over the waterways. During the lean months many tributaries dry up so that walking on mud roads and over fields becomes the only option to reach most villages (**Fig.1.3.**).

5.2. Large populations :

Fig.1.2 : Bangladesh— a land of rivers

Fig.1.3 : Most village homesteads are reached by foot

5.2. Large populations :

The estimated population of Bangladesh is 103 million (1986 census report), with a projected 166 million by the year 2005. The population of children under 15 years of age in 50.6 million, 18.3 million being under 5 years of age (**Fig. 1.4.**). The average life expectancy is 50 years. With a population density of 717 per sq. kilometre total area, it is one of the most densely populated countries of the world. To put the statistics into perspective, some socio-economic indicators of Bangladesh, and its neighbouring countries Nepal, India are given in **table 1.1.** Statistics of USA is given for comparison.

Fig.1.4 : Almost half the population comprises of children.

Table 1.1 : Comparison of Social and Economic Indicators in Bangladesh, Neighbouring Countries and the USA.

	Bangladesh	Nepal	India	USA
POPULATION				
Population (1986, Millions)	103.2	17	781.4	241.6
Growth (%)				
1965-80	2.7	2.4	2.3	1.0
1980-86	2.6	2.6	2.2	1.0
1986-2000	2.5	2.5	1.8	0.6
Size of Stationary Population[a] (Millions)	342	63	1,698	279
Urban Pop (% Total 1985)	18	7	25	74
AREA AND DENSITY				
Total Area (1000 sq km)	144	141	3,288	9,363
Arable Land (1000 ha)	8,891	2,290	164,850	187,881
Pop per sq km Total Area	717	121	238	26
Stationary Population	38.5	27.5	10.3	1.5
ECONOMIC AND SOCIAL INDICATORS				
GNP Per Capita (US$)	160	150	290	17,480
Growth PC GNP (1965-85)	0.4	1.9	1.8	1.6
Life Expectancy at Birth (yrs)	50	47	57	75
Daily Calories Per Capita (1985)	1,804	1,997	2,126	3,682
Infant Mortality (Per 1000 Live Births)				
1965	153	184	151	25
1985	121	130	86	10

[a] Stationary populations are expected by the end of the next century.

Sources: World Bank (1988), World Development Report 1988; Food and Agricultural Organization, Production Yearbook 1985.

5.3. Fragile primary health care infrastructure :

The health care system of Bangladesh could be described as being centralized with an urban curative focus and little effective penetration into the rural sector where the majority of the population resides. Per capita expenditure on health is still very low and most of the population have little access to modern medicine. The last two decades have however shown a slow decline in infant mortality rates (**Table 1.2.**), which is encouraging.This has emerged from the growing committment of the health planners to PHC and equitable distribution of resources, mainly as a long-term strategy for population control (Rahman, 1989).

The physician to population ratio is very low; almost 80% of doctors are concentrated in

Table 1.2 : Comparison of Health, Population and Welfare Indicators in Bangladesh and Neighbouring Countries.

	Maternal Mortality (per 100,000 live births)	Infant Mortality (per 1000 live births)		Population per Physician		Population per Nursing Person		Babies with low birth weight (percent)	Dependent population %<15 yrs	Total Fertility Rate
	1980	1965	1986	1965	1981	1965	1981	1984		
Bangladesh	600	153	117	8400	9690	—	19370	50	46	5.5
Pakistan	600	149	111	—	2910	9910	5870	28	43	6.5
India	500	151	86	4880	3700	6500	4690	30	38	4.3
Sri Lanka	90	63	29	5800	7460	3210	1260	25	35	2.7

* Third Five Year Plan, Government of Bangladesh 1985-1990.

urban hospitals and private clinics. Para professionals like nurses are grossly inadequate in number, demonstrated by the number of physicians exceeding the number of nurses by a large margin.

There are no organised systems of collecting vital information such as birth and death registrations. More than 90% of births are at home, attended by relatives and/or traditional birth attendants.

In recent years some vertical programmes have had limited success and this could be taken as an indicator that it is chiefly through the strengthening of PHC programs that better health could be achieved in future. Immunisation rates have increased recently from a non-existent statistic to more than 50% in some areas.

All these factors indicate that there is no formal infrastructure of health care and services within individual villages. The same applies even to inner city 'unofficial' squatter populations, where conditions in most of these countries are even worse than in rural areas (Harpham et al, 1985) (**Fig. 1.5.**). Similarly, all health input comes from exogenous sources

Fig.1.5. : A deprived area in Dhaka city where children were seen.

without any effort to motivate the local residents, again a common criticism about health delivery system in many countries (Nondasuta and Husdee, 1990).

5.4. The quality of medical education and training of doctors:

The continued emphasis on a physician-centred health system is exemplified by the marked bias in expenditure favouring the training of medical doctors over other types of allied health personnel (Gish, 1981). The undergraduate curriculum is heavily biased towards clinical medicine with an emphasis on diseases more relevant to developed countries (Zafrullah Chowdhury, personal communication). Paediatrics is a new field, recognised formally only in the last two decades and having low priority in the curriculum. Needless to say, sub-specialties such as developmental paediatrics and paediatric neurology are unrecognised fields for postgraduate training.

In developed countries it is well-recognised that assessing children for developmental and neurological problems requires training and experience (Bennett et al, 1984; Martin, 1984). When this is lacking, and given the logistic constraints prevalent in developing countries such as Bangladesh, the development of simple procedures for assessment that would aid the physician, finds a rationale.

5.5. The cultural milieu - nature versus nurture? :

Despite the poor vital statistics and level of PHC, the Bangladeshi society, of which 85% is rural, is based on communality with long-standing traditions of being hospitable and exercising neighbourly duties, filial piety and religious codes of ethics. In inner-city underprivileged populations these values are, understandably, somewhat eroded.

Metaphors such as 'all fingers are not the same size' are used for describing a disabled child. This attitude propagates a nurturing attitude; similar attitudes can be found in other cultures (Miles, 1990). Differentially, some disabilities are given more status, such as blindness. Children with other disabilities, such as epileptics, prefer not to be stigmatised, a

feature also seen in Western culture (Shorvon and Farmer, 1988; Bevan, 1985; Taylor, 1987). Covert problems such as deafness or mental retardation are simply unrecognised in their milder forms, the person blending in with the normal population.

It is common to seek help from traditional healers, shamans, mystics, fakirs and hakims (Kakar, 1982). Even though a very small percentage of population ever come in contact with an 'allopathic' doctor, they are nonetheless regarded as 'magic' healers, armed with their medicine and mixtures.

In planning studies within these communities, some important issues are raised that have methodological significance. Firstly, the general level of hospitality to strangers and the over-hospitality shown toward doctors (in the hope of a magic cure to a variety of ailments that the doctor has to see out of respect to the members of the community) can be time-consuming, drawing upon the already limited time available for actual work, but necessary and polite.

Secondly, the labelling of children with mild disabilities and impairments which are not perceived as problems within the community, may be stigmatising and harmful for their development. Yet these are the children who would most benefit from some form of treatment or intervention. It has been suggested that the focus should be on more severe problems to begin with, extending services to the mildly impaired gradually, once the confidence and faith of the community has been established (Miles, 1990). Societal expectations about a disabled child would also differ from Western cultures where much importance is given to individual development and achievement (Levine, 1980). In cultures such as Bangladesh, more emphasis would be put on 'getting along' or 'being considerate' or 'helping the mother in household chores/ helping the father in rowing a boat' (Munir, 1990, unpublished). That is, daily living skills and harmonious interaction with family, neighbours and peers hold more value.

Thirdly, respect must be given to the indigenous healers who have helped to nurture the disabled child and provide solace to the family traditionally. Their help may be incorporated into primary health care and rehabilitative programs (Young, 1983), not dissimilar to the recent trend in training and utilising traditional birth attendants (TBAs) in perinatal medicine

(Mangay-Maglacas and Pizurki, 1986).

6. Rapid epidemiological assessment of childhood disabilities :

It is apparent that the present situation of disabled children in developing countries still remains unaccounted for. An important reason is the lack of basic information of the prevalent causes, types, extent and distribution of the problem. Yet such information is necessary for formulating policies, planning programmes, and for allocating scarce resources. It is also evident from the logistic constraints present in these countries, that any method of case identification must be easy and designed for use by lesser trained personnel.

Attempts have been made to standardise simple methods of screening for childhood disabilities in children aged two to nine years using community workers (Belmont, 1986). The procedure was found to be highly sensitive, but with large numbers of false positives. To further refine the screening procedure, a three-country study was conducted in 1987-88, called the 'Rapid Epidemiological Assessment of Childhood Disabilities' (REA) which is described in Chapter 2.

The REA study required those children who were screened as positive for a disability and also a number of children who were screened as negative, to be seen by a team of professionals, including paediatricians and psychologists. In designing the format for the neurodevelopmental assessment the constraints in carrying them out in field situations, ie. village homesteads or city community centres, were foreseen, in view of the logistic constraints outlined in the previous sections. Whilst maintaining the format of a comprehensive assessment a possible solution to help overcome some of the constraints was formulated. The next section discusses standard neurodevelopmental assessments in developed countries, and the possibilities of introducing simpler procedures within it.

7. The Neurodevelopmental Assessment:

Although there is no universal standard format, there is a basic consensus about the

principles of neurodevelopmental assessment. A multifactorial approach is used based upon the quantitative and qualitative evaluation of several streams of development (Illingworth, 1972; Capute and Biehl, 1973; Bax and Whitmore, 1987), and based upon concepts drawn from developmental psychology, neurology, neurobiology, psycholinguistics, etc. (Farber et al, 1985). The developmental paediatrician's greatest strength is in using information from the history, and general and neurological examination in interpreting developmental observations (Holt, 1991).

The purposes of the developmental assessment are usually for confirming a diagnostic entity, documentation of developmental status, or prescribing appropriate intervention or treatment. A criticism of this assessment procedure is that whereas the diagnosis or documentation of status requires assessment that is typically formal and standardised, prescribing individual treatment can be highly informal and indiosyncratic (Wachs and Sheehan, 1988).

The traditional neurological examination (Baird and Gordon, 1983) is an integral part of the developmental examination. In population based studies for developmental screening, it is of greatest value for children who are screened as being 'at-risk' for disability and are referred for evaluation, than for normal controls; and the more severe the disability, the more likely that there will be a neurological abnormality (Drillien and Drummond, 1983 pp.125-136). One may conclude that normally functioning children will least benefit from the examination.

On the other hand, every 'at-risk' child needs thorough evaluation. As Kenneth Holt (Holt, 1991 p.161) states, 'there are no short cuts or quick tests in satisfactory developmental practice. To be able to give a reliable opinion that a child is normal, to make a sound developmental diagnosis and to provide acceptable developmental guidance, personnel must be well trained'. To exemplify this, in countries such as Great Britain every child who is 'at risk' for disability is seen by a trained developmental (community) paediatrician (Goodwin, 1990).

Time and training are thus crucial for valid assessments to be done. Both these factors, as has been noted in earlier sections, are in short supply in developing countries. To make best use

of the physician's time, intermediate steps in evaluation are needed to reduce the number of children who require a more detailed assessment. This is especially justified in neuroepidemiological studies where large numbers of children are expected to be normal.

Some intermediary tests that are used in the field of paediatrics are reviewed below, to see whether their conceptual principles can be adopted for use in the identification of childhood disabilities. The procedures are presented as being 'functional' in their approach, and are used in aiding physicians, community workers and the general public in the identification of both acute and chronic ailments in infants and children.

8. Review of functional tests :

'Function' as defined by the Oxford Dictionary means 'the special activity or purpose of a person or thing'. The word is used in medical literature as a generic term, interpreted differently in the varied contexts in which it is used. This makes it a difficult task to review existing literature. For practical purposes, four groups of tests have been reviewed, each group having 'functional' qualities in terms of (1) assessing functional capacities in children (2) being functional by virtue of their briefness (3) being functional in their objective measurement (4) being functional in their task performance. An important characteristic of such tests are that they have the possibility of being used by poeple other than doctors.

8.1. Tests based on observation of functional capacities of children:

Two models have been developed in the United Kingdom to facilitate the documentation of children's abilities and disabilities. The earlier of these systems was proposed by Holt (1957) as a means of drawing a 'profile of disabilities. The profile will show the nature of help needed by the handicapped children and will allow the selection, from a group, those children who will benefit from a particular form of assistance' (p.226). The model is known as the PULHESTIB system, based on the initial letters of the nine functions that are assessed. These functions are (P) physique, (U) upper limbs, (L) locomotion, (H) hearing, (E) eyes, (S) speech, (T) toilet,

(I) intelligence, and (B) behaviour. Each function is divided into 4 grades, with 1 representing normal functions and 4 complete absence or impairment of function. As Holt (1957) showed, the PULHESTIB system may be particularly useful in documenting the case history of a particular child. A similar system, known as PULSES, has been used in a study on the treatment of cerebral palsy (Goldkamp, 1984).

A second model, proposed by Lindon (1963), involves a format that resembles the PULHESTIB system but was designed to emphasise positive functional capacities and to increase the sensitivity of the grading of each function. According to Lindon, 'the PULTIBEC System was evolved as an attempt to fulfull the recognised need for a global, yet concise, system for coding the difficulties of children with multiple handicaps in functional terms' (p. 143). The functions assessed by this system are (P) physical capacity, (U) upper limbs, (L) locomotive, (T) toilet, (I) intelligence, (B) behaviour, (C) communication. Each of these functions is graded from 1 to 6, the former denoting normality and the latter functional uselessness. A very useful feature of the PULTIBEC system is that several functions are subdivided to permit greater specification of function. The value of the PULTIBEC system is that it provides a 'profile of a child's functional abilities which can be read at a glance' (Lindon, 1963, p.126). The system can also be used to document changes when repeated assessments are made of a child. The PULTIBEC has been used by non-doctors in field surveys of childhood disabilities.

A somewhat similar screening instrument (Perceptions of Developmental Skills Profile) has been used to assess the prepost gains of handicapped preschool children (Bagnato, Neisworth, and Evans, 1978).

Problems for using the above models of assessment is that they are time-consuming and need considerable training and experience to perform and are best done in quiet environments such as in child development clinics. However, all the systems exemplify the concept of quantifying functional skills as the central focus of attention rather than the nature and aetiology of the underlying condition. Another point in favour of identifying functional skills is that it

would correlate well with the disability coding in the International Classification of Impairments, Disabilities and Handicaps (WHO, 1980), which aims to 'present a profile of the individual's functional abilities' (p. 37).

There are other tests of function that have not been discussed as they usually look at specific abilities or domains of development, eg. tests that look at motor impairment only (Gubbay, 1975; Stott, Moyes and Henderson, 1984). Most IQ tests also fall into this category.

The merits of direct observation may be mentioned here, as all the above-mentioned tests rely on it. For the more qualitative aspects of the child's development, the interaction between mother and child, between the child and peers, and the child and the surroundings, direct observation gives invaluable information (Cooper, 1974; Illingworth,1987). The same may also apply for other aspects of assessment such as the neurological examination. As Brett says succinctly, 'observation of spontaneous and elicited manipulation and gait gives much helpful information about the integrity of the child's nervous system. This is true even of the child who is uncooperative either because he is in a bad mood or is emotionally immature in keeping with a degree of mental retardation. Thus, to quote an extreme case, the speed and accuracy with which a retarded child snatches the doctor's spectacles from his nose can make it clear that there is no motor defect such as weakness, incoordination or involuntary movements, even though a formal demonstration of this is impossible' (Brett, 1991, p.36).

8.2. Tests that are functional in their briefness:

The second category of tests used in assessing children are those that are 'functional' in terms of their briefness and easy scoring methods based upon clinical observations. This quality makes them easy to use in situations where quick decisions are required to be made regarding diagnosis and treatment. Although used in acute conditions, the basic principles of converting clinical impressions into simple scores seem conceptually akin to the procedure this study was hoping to develop.

The Apgar score, a much used and widely accepted test, exemplifies this (Apgar, 1953).

Virginia Apgar's contribution to clinical measurement lay in her effort to replace subjective clinical impressions on the condition of the newly born infant with objective observations, which are summarised in a single index according to a simple set of rules. It has been used for all three clinical purposes, ie. discrimination, prediction and evaluation, and despite the advent of modern technology it still remains unsurpassed as a clinical tool to serve the first purpose of discriminating between infants who require cardiopulmonary resuscitation and those who do not (Schimdt et al, 1988). Its value as an indicator of 'birth asphyxia' and a predictor of developmental outcome is not wholly convincing (Chamberlain and Banks, 1974; Sykes et al, 1982).

In developing countries, diarrhoea and acute respiratory infections are the two major killers of infants and young children. Early detection of the conditions and prompt intervention have been shown to reduce mortality considerably. Field studies have provided important clinical markers for both these conditions. For example, the **respiratory rate** is used to discriminate children who require symptomatic treatment, oral antibiotics, or injectable antibiotics and hospitalization (WHO, 1990). **Watery diarrhoea** has been used as an important marker for treating the child with home-made oral rehydration saline (ORT) by mothers and family in developing countries (WHO, 1980c).

These are examples of brief and simple methods of detecting these easily treatable but potentially fatal conditions, and are the fruits of scientific observations made from laboratory experiments and field surveys. Although it is presumptuous to say that one can devise similar methods of detecting childhood disabilities, which are long-standing conditions, the simplicity of such indicators makes them conceptually attractive in the possibilities they present. One may ask hypothetically if, in communities where doctors are a rarity in themselves, family members, mothers, and health workers or their equivalents can discriminate disabled from nondisabled by observing children performing simple tasks. The earlier the intervention, whether it be nutritional (eg. Vitamin A-rich food), medicinal (eg. treatment in epilepsy), rehabilitative (eg aids in post polio paresis), or social (eg, increased communication in mentally handicapped

child), the better the future prospects of the child to survive productively.

8.3. Tests that are functional in their objective measurements:

Objective measurements are quantifiable and aim to be more reliable than subjective impressions. In the field of disability objective tests such as pure tone audiometry or measures of visual acuity have been shown to have good correlation with the functions of hearing and vision respectively. Similarly, measurements of joint range of motion has been used to evaluate joint disability (Milch, 1959) and cerebral palsy (Bleck, 1979). Johnson and Ashurst (Johnson and Ashurst, 1989) have demonstrated the value of measuring the popliteal angle in infants by health visitors to identify cerebral palsy, although the overall impression of the health visitor was a much better predictor than the test on its own. The value of quantifiable measures is that non-doctors can be trained to use them, but the disadvantage is that they can only be used along with other general indicators.

8.4. Tests that are functional in the tasks performed— criterion referenced testing:

Included in this category of functional tests are those that have been advocated by educational psychologists for use in testing children with learning difficulties and mental retardation in developing countries (Baine, 1988). The testing involves skills that have direct instructional validity, ie. the degree to which a test assesses specific skills learnt/taught. For formulating appropriate tests, ecological inventories are made to identify functional tasks a person is required to perform within his/her environment. Then each task is broken down to component parts (ie. task analysed) for scoring. The tests may be used for screening, as a brief preview of the person's achievement; they might be used as achievement tests to identify the particular skill a person does or does not possess; they can be used as diagnostic tests, as indicators of the specific type of remedial training required by the child, eg. specific placement. They may be especially helpful for monitoring a child's progress towards the set goals and for

evaluating the impact of a particular intervention.

These tests are called Criterion Referenced Tests (CRT) (Popham, 1978). The scores of the tests are based on whether the child passes or fails the task (criterion) set out, and judged on its own merit. Such an assessment is without reference to other aspects of the profile of abilities or to the age at which other children achieve a given level of competence on the task or skill. This is in contrast to the Norm Referenced Test (NRT), where overall achievement of the child is represented by a score that is compared to standardised scored of the population (Popham, 1978). In developing countries, NRTs have more value in measuring problems of a biological nature such as height and weight, and have been used as a key element in the UNICEF stategy of using Growth Charts (Grant, 1984). However, given the diversity of gender roles, sites (eg. urban versus rural) and different social strata, standardisation of norm-referenced developmental tests and IQ-testing in developing countries is of less practical value (Serpell, 1988).

9.Designing the 'Observation of Function' :

The term 'function' has different connotations in the context it is used, as noted in the preceding sections. Some tests may be functional in the complete profiles they present of the child at a given time so that concrete measures can be formulated for placement or intervention; some are functional in being quick, at the same time being accurate - most of these tests are used for identifying acute paediatric problems; some tests are easy and objective (ie. quantitative) in their measurments, hence functional; some are functional in the skills they measure which have ecological relevance to the child and helps in knowing what skills to teach.

However, to help physicians in doing comprehensive neurodevelopmental assessments in field settings, there does not seem to be a test that incorporates most of these characteristics, to help identify disabilities of gross motor, fine motor and vision, speech and hearing, and cognition, within a short period of time. For this study, the 'Observation of Function' was

designed as such a procedure to determine whether it could be used by medical professionals on one level, and non physicians on the other, for identifying disabling problems in children.

In the test structure, the concepts that were derived from information presented in the previous section, were that it was brief; it was based on a single task and scored on it, hence criterion- referenced; it was functional in its ecological validity ie. the task was common to most children and used local material; it looked at several areas of functioning, and although not extensive to 'profile reference' a child, scored on different domains of development; and non-doctors could be trained to use it.

10. Objectives of the study:

The principal objective of the study was to develop a procedure that might strengthen methods of evaluating large numbers of children for disabilities in developing countries at two levels. Firstly, in aiding assessments at a very practical level, either physicians doing neurodevelopmental assessments or non-physicians doing simpler screening and evaluation, in terms of saving time, so that more time may be spent on doing indepth assessments of those children who fail the test. Secondly, in indicating the value of evaluating children holistically, by observing them perform a natural function that is not done as a formal procedure in paediatric practice. The first objective has practical value and the second, conceptual.

11. Specific aims of the study:

1) To verify whether the 'Observation of Function' can identify serious disabilities in general,and motor disabilities in particular, in children, within the format of the neurodevelopmental assessment, validly and reliably.

2) To verify whether the procedure can screen for those children who require the neurological examination.

3) To verify whether the same procedure can be used by community workers to identify disabilties in general, and motor disabilities in particular, validly and reliably.

12. The time period of the study:

The field work of the study was done in two parts. The **first part** was conducted as part of an epidemiological study of childhood disabilities in five sites in Bangladesh in 1987-88. It was designed to obtain results which would verify the first two aims of the study. The **second part** was conducted in 1989 in only one of the previous sites, as a follow-up study. The last aim of the study was to be verified within it.

Henceforth the first and second parts of the study shall be referred to as **part A and partB** respectively.

CHAPTER TWO

'THE RAPID EPIDEMIOLOGICAL ASSESSMENT OF CHILDHOOD DISABILITY': AN INTERNATIONAL COLLABORATIVE STUDY IN THREE DEVELOPING COUNTRIES

Introduction

The chief purpose of this chapter is to provide a methodological backdrop for the thesis, which evolved from the larger epidemiological study of childhood disabilities. The first two sections discuss issues regarding the value of population based surveys, the problems that are associated with conducting them, and possible ways of confronting them. The third section describes the main study, an international collaborative study done in Bangladesh, Jamaica and Pakistan in 1987-88, called the 'Rapid Epidemiological Assessment of Childhood Disabilities', and presents initial results from Bangladesh.

1.Epidemiological information on disability and its uses :

From the discussion in Chapter One it is evident that basic information on the prevalence and distribution of childhood disability in a community is needed before appropriate services for prevention and rehabilitation can be planned and implemented. The specific significance of such information is discussed below.

1.1.Prevalence:

The prevalence of childhood disability refers to the proportion of children in the community who are disabled at a given time. It is the function of two community parameters - one is the **risk** of becoming disabled and the other is the average **duration** of disabilities that occur. Duration ,in turn, is influenced by the probability of surviving once disabled and by the availability of therapy for curable conditions. It is likely that the risk of becoming disabled is elevated for children in developing countries because of the excess exposure of many children

to serious infections (eg. meningitis, polio) and nutritional deficiencies (eg. iodine, Vitamin A deficiency) (Durkin et al, 1990). Increased mortality of children once disabled due to these conditions might, on the other hand, reduce the rate of serious disability in these communities. Appropriate screening programs are needed to provide knowledge and insight into the magnitude of the problem.

1.2.Distribution:

The distribution of childhood disabilities refers to their geographic occurrence (eg. rural, urban, mountains, plains) and their frequency in different social categories (eg. boys, girls; younger children, older children; poor families, wealthier families) as well as to the relative frequency of the different types of disabilities (eg. blindness, deafness, movement disorders, cognitive disability), of different grades of severity (mild, moderate, severe), and of different causes (eg. genetic, infectious, nutritional, traumatic) (Durkin et al, 1990).

Knowledge about distribution serves two purposes.One is to give clues about **risk factors** of conditions for which the aetiology is not well understood, and the other is to provide a basis for **targeting services** for prevention and treatment. For example, in an area known to be endemic for goitre due to nutritional iodine deficiency, an excess of motor disorders associated with mental retardation and hearing loss should guide investigators and public health planners to suspect cretinism. The occurrence of peripheral neuropathy which is quite uncommon in childhood would cause planners to search for a toxic exposure, eg. lathyrism.

1.3.Specific information about therapeutic needs and resources:

Simply collecting information about prevalence and distribution would not be sufficient for developing appropriate plans for services. Additional detailed observations are needed to provide answers to questions such as the following:

To what extent are the special needs of children already being met informally within the family or the community?

Do disabled children tend to be socially accepted and integrated, or socially isolated? How does the disability affect the social standing of the family?

How do variables such as age and gender of the child, socioeconomic status of the family, literacy, economy of the community, and type and severity of the disability influence the answers to these questions?

What resources within the family and the community could be mobilised to meet the needs of disabled children?

What are the overall therapeutic and educational goals and needs of disabled children and their families?

2.Considerations regarding the collection of basic information on childhood disabilities in the community :

Where formal services for evaluating and providing for the special needs of disabled children are scarce or non-existent, there are many problems in collecting such information. These problems also dictate methodologies that are adapted for population based studies and are discussed here.

2.1.Data sources and methods of collection:

In developed countries epidemiologic studies of disability typically rely on computerized data available from **service records** from **registries** containing information on all causes of a specific kind of disorder, or from organised studies that follow a birth **cohort** of several thousand children (Davie et al, 1972; Drillien and Drummond, 1983; Gustavson et al, 1978; Hagberg, 1987; Nelson and Ellenberg, 1986; Stewart-Brown and Haslum, 1988).These methods are reasonably valid for serious disabilities in communities where services and records or registries are widely and uniformly available. Even then, there is under-ascertainment in some groups, and comparisons between communities and especially between countries are problematic because of differences in definition of disability and completeness of coverage and

reporting (Haerer et al, 1986; Pharoah and McInlay, 1986; McLaren and Bryson, 1987). In most developing countries these sources of data are not readily available, and because of very different circumstances, information from Western countries cannot to transferred to developing countries. Instead, special efforts have to be made to collect baseline information.

Any method of case identification that is to be used in developing countries must be at once inexpensive, simple, rapid (because of the large numbers of children to be screened or evaluated), and accurate. The requirement of reasonable accuracy is the most difficult to satisfy.

Two low-cost methods have been found to be unsatisfactory because they miss too many children. One of these methods involves adding a question on the **national census interview** which asks whether anyone in the household is disabled. This approach tends to under-enumerate disabilities that are not highly visible (such as hearing loss and mental retardation) and disabilities in women and children (Chamie, 1986).

The other low-cost method that has been tried is to ask **key informants** in the community (eg. community leaders, teachers, healers, midwives) to identify all disabled persons in the community.This method was studied in several countries and found to be inaccurate (Belmont 1984; Thorburn et al, 1989). There is serious under-enumeration especially of less physically obvious conditions.

A third approach involves **door-to-door household surveys** with screening of children for disabilities and follow-up professional evaluations of selected children. This is the approach that is used in the study described in the later part of this chapter.

Before describing the study, a number of considerations and decisions to be made in undertaking surveys of childhood disabilities are discussed.

2.2.Sampling:

Sampling, which refers to the selection of a subset of individuals from a population, is a technique employed in many surveys to reduce the number of observations that must be made

in order to make valid generalisations about the larger population (Lemeshaw and Stroh, 1988).

The sample must satisfy two requirements. First, it must be large enough to obtain statistically stable estimates of prevalence and distribution. Because the prevalence of each specific type of disability is relatively rare (usually less than 5%), a sample size of at least 5,000 may be required. Second, results will have to be suitable for generalisation. If the sample included only children attending school, for example, it would probably exclude many children with severe disabilities and would not be representative of all children in the community (many of whom do not go to school).

An alternative to sampling is to do a 'blanket' survey of an entire community, acknowledging that inferences made from the survey apply only to the particular community surveyed. This approach may be preferable to a probability sample of a larger area if the goals of the survey are not only to study the epidemiology of disability but also raise community awareness of disability, to stimulate community-based rehabilitation and to provide a basis for referring disabled children to appropriate services.

2.3.Reliability and Validity:

The **reliability** of a method of identifying cases refers to the extent to which the method generates repeatable results. For example, a questionnaire would be considered unreliable if it gave inconsistent results when administered on repeated occasions for the same children (provided there was in fact no change in the disability status of the children) (Fletcher et al, 1988).

The **validity** of a method of case identification, on the other hand, refers to its accuracy. If the method is a procedure for screening children, it will generate results that can be classified into four categories: **true positive** (truly disabled and positive on screen), **true negative** (truly not disabled and negative on screen), **false positive** (truly not disabled but classified as positive on screen), and **false negative** (truly disabled but classified as negative on screen). A valid screening procedure, of course, is one that correctly classifies a very high percentage of

the children as either true negatives or true positives (Fletcher et al, 1988).

2.4. The focus on disability:

Impairment, disability and handicap are terms used to describe stable persisting disorders. Fully operationalised by the World Health Organisation (WHO, 1980b) in its international classification, **impairment** refers to an underlying molecular, cellular, physiological or structural disorder within an individual. **Disability** refers to a stable and persistent deficit in function, often the consequence of an impairment, and also confined to the individual. **Handicap** is the limitation on carrying out social roles defined as appropriate for an individual of certain age, gender or class.

There is an apparent inherent hierarchy, a continuum, in the ordering of impairment, disability and handicap. For example, an impairment may lead to a disability, although not all poeple with and impairment need have a disability; disability may lead to a handicap, although again all those with a disability need not have a handicap. Thus, the relation is not one to one. Neither is the relationship unidirectional, as would be expected. In fact, there can be disability without impairment, and handicap without disability. An example of the former is most evident in the case of mild mental retardation, or cultural familial retardation, where a disability is present in spite of no obvious impairment. Similarly, poeple with specific diseases, for example epilepsy or leprosy, suffer from handicap because of stigma attached to the impairment even though they may not be disabled.

In the study of stable persistent disorders, the assessment of impairment is an absolute, and standard tools can be used across all societies and cultures. The tools to assess disability are usually culture-specific, because different societies have different cultural norms and expectations of their children. Valid assessment of disabilities may be possible if due consideration is given to cultural differences. The assessment of handicap is dictated by external factors, as it is manifested by an interaction between an individual and a society.

The focus on **disability** rather than **impairment** is appropriate because a multitude of

impairments whose aetiologies may differ greatly can lead to a specific disability. While the assessment of disability (either for the treatment and rehabilitation of the individual child, or for the estimation of prevalence), can be relatively straightforward, the assessment of impairments may require sophisticated tools. In the medical setting, frequently, a physician cannot diagnose an impairment without specific diagnostic tools. For example, even though the presence or absence of movement disability can be assessed by observing the child's gross and fine motor functions, it is not as easy to assess the cause of movement disability, or the associated impairment. Movement disability could arise due to cerebral palsy, polio or other infections, specific nutritional deficits (eg. iodine), gross nutritional deficit, trauma or a variety of other causes.

Some of the **causes of disabilities** under review that are thought to be useful for the purposes of the study described later, are listed in **table 2.1**. As can be evidenced from this table, similar disabilities can arise from different causes, and in the same way, a specific cause can lead to disabilities which are manifested in different forms. There is neither specificity of cause or specificity of effect. The search for the causes and the knowledge of the impairments leading to specific disabilities are important in order to prevent disabilities. However, as a first step, it should suffice to estimate the magnitude of the problem, and to provide whatever services can be offered to the identified children. Another important reason to focus on disability rather than impairment is that impairments do not always lead to problems which require services or care.

The focus on **disability** rather than **handicap** is thought appropriate because the study of handicap is more sociological than neuroepidemiological. The presence and degree of handicap, given a disability, is determined by the interaction between the individual and the particular society. A mild disability, let us say of movement or balance, can be a substantial handicap in areas of difficult terrain, without proper roads. In developed societies where there are now numerous facilities (wheelchairs, ramps, elevators, 'kneeling' buses, etc.) this disability may no longer be considered a handicap. Again, two people in a particular society may have the

Table 2.1: Causes leading to the specific disabilities under study

(The causes of disabilities listed here are not exhaustive. They were compiled with emphasis being given to the causes of disabilities in developing countries.)

1. Movement disability
Infectious causes e.g. polio, tuberculosis, osteomyelitis, tetanus, meningitis and encephalitis (esp. measles, shigella), Guillain-Barre syndrome
Deficiency diseases e.g. iodine deficiency disorders (cretinism and hypothyroidism)
Neurological diseases e.g. severe mental retardation and cerebral palsy (due to a number of causes)
Poor perinatal care e.g. birth asphyxia, birth trauma, premature deliveries, low birth weight and intrauterine growth retardation (causing developmental delay)
Inflammatory and toxic neuropathy e.g. lathyrism
Inherited or genetic disorders e.g. muscular dystrophy, chromosomal anomalies
Structural defects e.g. talipes, spina bifida
Others e.g. rheumatoid arthritis

2.Hearing disability
Conductive hearing loss, e.g. chronic suppurative otitis media, non-suppurative otitis media and Eustachian Tube disorders and others
Infections, e.g. congenital rubella syndrome and other prenatal infections, meningitis, encephalitis
Disorders originating in the pre(peri)natal period, e.g. intrauterine hypoxia/birth asphyxia
Nutritional disorders, e.g. neurologic cretinism
Hereditary deafness, e.g. recessive or dominant
Chromosome anomalies
Others

3. Vision
Nutritional disorders, e.g. Vitamin A deficiency (Xerophthalmia)
Perinatal infections, e.g. rubella, toxoplasmosis, syphilis
Postnatal infections, e.g. trachoma, Tubercular meningitis, encephalitis
Genetic causes, e.g. chorio-retinal degenerations, retinitis pigmentosa, optic atrophy, retinoblastoma, cataracts
Metabolic disorders, e.g. galactosemia
Others

4. Speech
Impairment of communication, e.g. mutism, autism, dysphasia
Delayed speech, both receptive and expressive
Dysarthria, problem with motor speech

5. Cognitive
Infections and toxic causes, e.g. TORCH infections, bacterial meningitis, viral encephalitis
Trauma, physical or chemical, e.g. lead, mercury, irradiation, maternal smoking and malnutrition
Nutritional disorders, e.g. iodine deficiency disorders
Gross brain disease (postnatal), e.g. subacute sclerosing panencephalitis
Unknown prenatal influence, e.g. hydrocephalus, microcephaly
Chromosomal anomalies, e.g. Down's syndrome, Fragile X syndrome
Genetic factors, e.g. single gene defects, as with PKU, Hunter's syndrome, Hurler's syndrome, Tay-Sachs syndrome
Gestational disorders, e.g. premature births, foetal growth retardation
Following psychiatric disorders, e.g. infantile autism
Environmental influence, e.g. cultural-familial mental retardation
Other

same degree of disability, let us say of movement, but one may be equipped with means to overcome the disability (education, ability to hire help, family support) and the other not. In less developed countries which do not have enough resources to meet the basic health requirements of the population, most children who have serious disabilities may be handicapped. This however needs to be studied, because some disabilities may be compensated for in these societies.

2.5.Range of disabilities:

Epidemiologic studies of disability in developed countries often focus on one type of disorder. Widening the scope to include more than one type of disability has advantages. Firstly, the yield and cost-effectiveness of the survey will be greater if more cases are identified. While the prevalence of one type of disability is likely to be low (often less than 1%), the prevalence of disability in general or of several types of disability considered together may be high (Rehabilitation International 1981; Durkin, 1989).

The second reason for including several disabilities rather than a single one in a survey is that at the level of the community worker, without sophisticated equipment and extensive training, it may be difficult to differentiate similar disabilities from one another. For instance, children that have communication problems due to mental retardation or due to hearing disability cannot often be differentiated easily (Mittler, 1981). In a study of hearing disability among children in a developed country, Parving (1984) found that many mothers were unable to diagnose a hearing problem among young children. The focus on multiple disabilities generates valid estimates by allowing the respondent more than one oppurtunity to give a positive response. For example, if the child has mental retardation, but the mother thinks that it is a hearing problem, she would perhaps not answer yes to a disability-specific question on mental retardation, but would answer 'yes' to the question on hearing. A second oppurtunity to classify the child as being a true positive is provided, whereas in the first case, he/she would be considered a negative, would not be followed up with a professional evaluation, and thus

would not benefit from whatever services that may be provided.

The third reason for including several disabilities rather than a single one is that the types of questions that identify one type of disability are also likely to identify other types of disability. For example, a child who is unable to follow directions may be mentally retarded, have a movement disability, a hearing disability, or in extreme cases, a vision disability.

The fourth reason is that one causal agent is sometimes responsible for more than one disability. In addition, the focus on several disabilities allows one to assess the degree to which children suffer multiple disabilities in a particular community and plan rehabilitation.

Lastly, for ethical reasons, it would be difficult to focus on one disability. This is especially so for research conducted in developing countries, where other disabilities among siblings or in the same child may be of greater concern. The researcher in such situations is often the first person to identify the health problems among the subjects, and may become the only link to services. When these services are rare and sought after, as are medical facilities, the burden on the investigator is great.

2.6.Grades of disability:

Another consideration regarding the scope of the survey is whether to target severe disabilities, mild disabilities or all grades of disability. An argument in favor of screening for milder conditions is that they tend to have the most favourable outcome after treatment and rehabilitation. This is true for vision disability caused by nutritional deficits or repeated insult by infectious agents (Brink et al, 1979; Brown et al, 1979; Tielsch and Sommer, 1984) and for hearing disability caused by chronic ear infections (Miller, 1983) or by central nervous system infections that effect hearing (Bloch, 1986). Ignoring the disability may result in permanent, and in some cases severe, damage.

At other times, not much can be done for the children who are identified. Mild mental retardation provides an example where identification might not be essential, as the syndrome is thought to be a result of under-stimulation of children in disadvantaged societies (Stein et al,

1986). The key evidence for this argument has been shown in Sweden, where a rise in the socioeconomic level of all in the society has lowered the rate of mild mental retardation (Hagberg, 1981).

On the other hand, an argument in favour of focussing on more severe disabilities is that these are the causes with most urgent need of care, and also *perceived* as problems by the community. Surveys of severe disability are also likely to be more accurate than those that include mild conditions, because it is easier to distinguish severely disabled children than to distinguish mildly disabled from non-disabled children (Hirst and Cooke, 1988), especially when community workers are interviewing mothers using simple instruments (cf. Section 3).

Once the technique has been perfected for identifying serious forms of disability, it could be modified further to identify cases with milder disabilities. Sometimes data on serious disabilities can be used to extrapolate the extent of mild forms of disabilities. For example, Dulberg (1987) has made a model by which the extent of iodine deficiency in a certain area can predict the proportion of neurologically damaged children that would be born, and given data on the higher grades of goitre to extrapolate and make an assessment of the numbers that have mild forms.

2.7.Two-stage Study Design:

In developing countries resources usually do not exist for all children to be seen by trained professionals familiar with assessing neurodevelopmental disability. If a valid procedure for diagnosing disabilities in children could be designed that was inexpensive (ie. did not require professional expertise), then a single-stage survey would be recommended.In the absence of such a procedure,a two-stage survey can be more cost-efficient.In Stage I, all children in the sample or population are screened using a procedure that is inexpensive and that is reasonably but not perfectly accurate.In Stage II a sub-sample of the children are followed for more expensive but definitive diagnostic evaluations (assumed to be perfectly accurate). In order to assess the validity of the screening procedure and to be able to estimate prevalence from the overall survey results, the sub-sample of children followed at Stage II should include children

positive on the screen plus a random sample of children negative on the screen (Shrout and Newman, 1989).

2.8.Screening by community workers:

The cost of the screening can be minimized by employing non-professional community workers to interview parents about the children, using brief, structured and simple questionnaires. Provided that the parents are satisfactory informants, and that the questionnaire is reliable and reasonably valid, this approach requires much less time and fewer resources than actual observations of children. Using community workers also has the added advantages of raising awareness within the community of disability and service needs, and of reducing the probability of cultural barriers between the interviewers and the parents that might result in misinterpretation and inaccurate results. It also trains a cadre of workers who might be available for further training and employment in community-based rehabilitation projects (Durkin et al, 1989).

2.9.Characteristics of the Survey Instrument:

The survey instruments (forms and questionnaires) used in community surveys of childhood disabilities would have to have the following characteristics (Durkin, 1990):

(i) They should be reliable ,valid and comprehensive (this means they should provide data with which to estimate prevalence, investigate distribution of disabilities in the community, and describe community needs and resources for rehabilitation and other services for disabled children).

(ii) They should be appropriate for use in different cultures and easy for interviewers to administer as well as for parents to understand.

(iii) They should provide data in a form that is convenient for researchers to process and interpret.

(iv) They should provide data that are comparable with findings from other studies.

3.'The Rapid Epidemiological Assessment of Childhood Disability' (REA) -an international collaborative study.

3.1.Introduction:

This study arose from a survey done in 1980 in ten developing countries, called 'The International Pilot Study of Severe Childhood Disability'. The aim of the study was to determine whether it would be possible to identify, by means of short questionnaires given by community workers to the caretaker (usually the mother) of the child, three- to nine-year-old children who had a variety of disabling or potentially disabling conditions. The results of the study showed that the screening questionnaire was sensitive to serious (moderate and severe) childhood disabilities. However, it lacked specificity: many more children were identified by the screen than those that had serious disability, although some of the children had milder forms of disability (Belmont, 1984). It also varied in specificity across sites (Flam 1989).

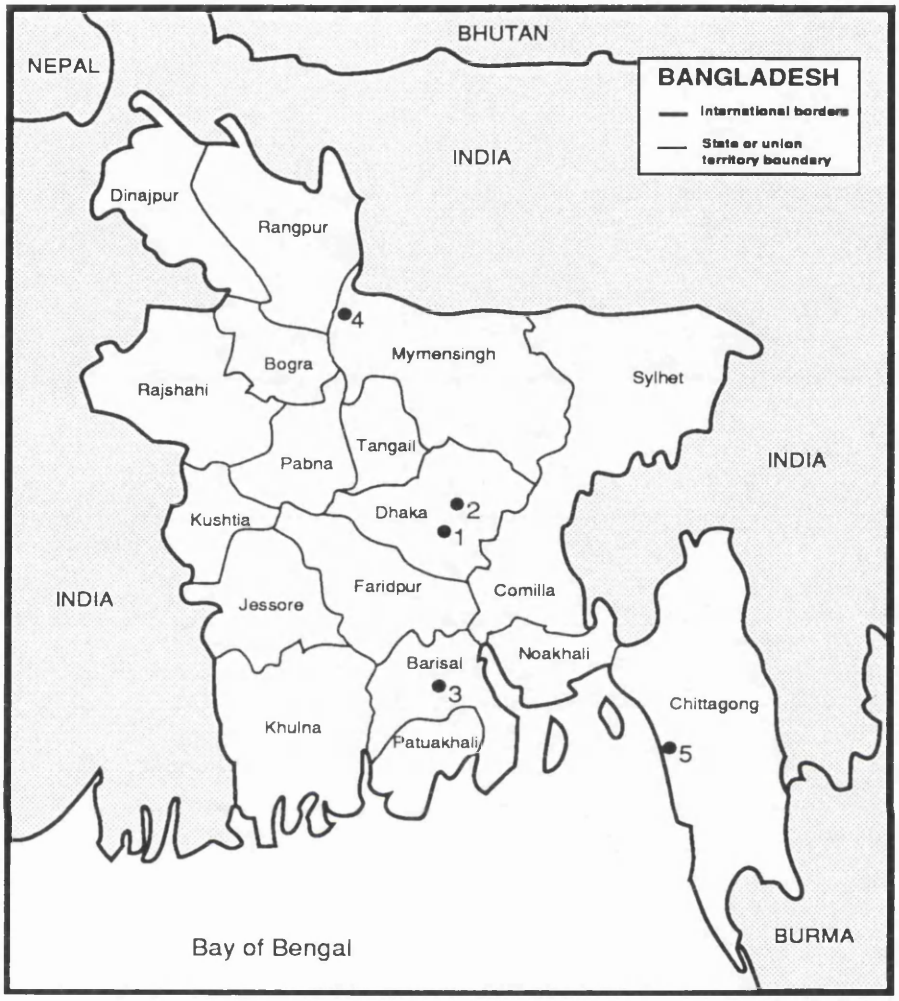
The REA study was done as a follow-up of the pilot study in three developing countries, Bangladesh, Jamaica and Pakistan, using the same screening questionnaire, modified to increase specificity. Following the recommendation of the pilot study the medical and psychological evaluations were also more fully developed. The primary aim was to standardise the screening questionnaire for diverse cultures using community workers. The secondary aim was to make estimates of prevalence and distribution of disabilities in the study sites and to identify putative risk factors.

3.2.Methods and procedures:

The methods and procedures described in this section were designed to detect six types of disabilities (movement disorders, mental retardation, vision and hearing disorders, speech disorders and epilepsy) in children between the ages to 2 and 9 years (inclusive). The overall purpose was to generate community-based data on prevalence, distribution, and rehabilitation needs and resources of children with these six types of disabilities. The reliability and validity

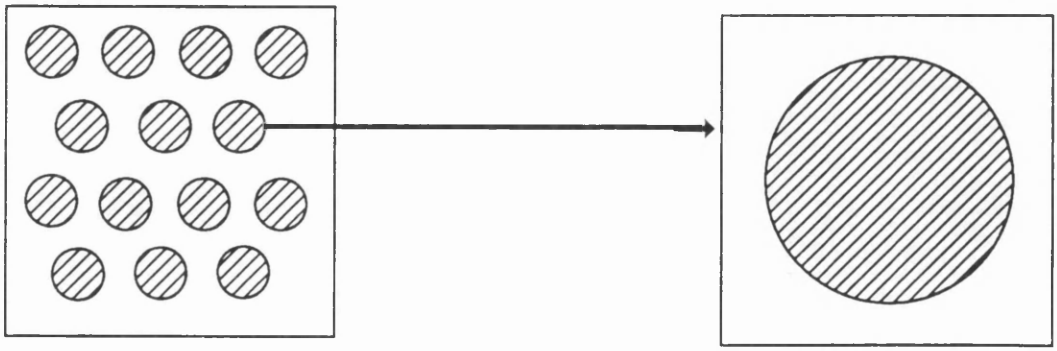
Fig. 2.1 : Sampling of children in the REA study

a) The 5 study sites indicated by dots within the map of Bangladesh



1 = Dhaka 2 = Dhamrai 3 = Barisal 4 = Kurigram 5 = Chittagong

b) Cluster sampling within each site



10 – 15 clusters per site

Each cluster "blanket surveyed" till number of children ~100 – 170

of the method was to be tested in the context of a two-stage study design.

The study as carried out in Bangladesh is described below.

3.2.1.Sampling:

The design called for drawing a base population of 10,000 children aged two to nine years from five sites in Bangladesh: Dhaka (site 1), Dhamrai Upazilla (site 2), Babuganj Upazilla (site 3), Ulipur Upazilla (site 4) and Chittagong town (site 5) (**Fig. 2.1a.**). A multi-stage cluster sampling method was used to select the study areas within each site. First, a number of clusters (15 per site) were selected randomly in each site (city, town or upazilla) (**Fig.2.1b.**). Next a household was chosen at random from within each selected cluster and then succesive contiguous households with at least one child in the target age range of two to nine years was selected for inclusion in the study until a total of 100 to 170 children were included from each cluster. **Table 2.2** enumerates the number of children included in each of the five study sites.

Table 2.2 : The Number of Children Screened in Each of the Five Study Sites.

Site No.	Site Name	No. of Children
1.	Dhaka	2,576
2.	Dhamrai	2,667
3.	Barisal	1,507
4.	Kurigram	1,025
5.	Chittagong	2,525
	Total	10,300

3.2.2.Description of the five study sites:

Dhaka (site 1): Capital city of Bangladesh, with a population of three million. There are large deprived areas with poor sanitation, no health surveillance facilities and mobile populations.

Dhamrai (site 2): Upazilla (sub-district) within Dhaka district, ie. 30 kilometres from the capital. All except one of the 15 clusters were rural villages. Most of them were inaccesible by car. Other means of transport used were boats and rickshaws. Many villages were reached only by walking.

Babuganj (site 3): Upazilla within Barisal district 300 kilometres from Dhaka. It is in the deltaic regions of Bangladesh near the Bay of Bengal. The area is completely rural. Many areas are inaccessible as it is inundated by rivers and streams. Most clusters were reached by walking, boat or rickshaws.

Ulipur (site 4): Upazilla in the northern district of Kurigram 500 kilometres from Dhaka. The area is rural and poor as droughts are common. However, most parts are more accessible as roads are better and land is drier. The area is hyper-endemic for goitre (Goitre prevalence survey, 1986).

Chittagong (site 5): This is a commercial town with the largest harbour in Bangladesh. There are large numbers of ethnic minorities and tribal poeple (Chakmas and Burmese immigrants) settled amongst the population.

3.2.3. The two-stage study design:

Stage I : Local people from the community were recruited to work as interviewers. These interviewers had to be able to read and write and to interact well with parents. They approached every household in the demarcated area and determined whether a two- to nine- year-old child lived there. For all households with at least one child in the target age range, the interviewer identified an adult in the household who knew the child well and requested his or her permission to be interviewed about the household and the child. After explaining the purpose of the study and obtaining permission, the interviewer completed three types of questionnaires for each household by reading the questions to the informant and writing down his or her responses. Most of the responses were coded and the interviewer simply circled the appropriate one.

The first questionnaire was a **Household Form (Appendix 1)** providing basic information about the composition of the household and socioeconomic characteristics (occupation of head of household, household possessions, type of floor material, source of water, etc.). One Household Form was completed for each household.

The second questionnaire was a **Mother-Child Form (Appendix 2)** which provided information about the mother of each child in the study, including her age, education, pregnancy history, and whether she was still living. One Mother-Child Form was completed for each mother with at least one two- to nine-year-old child residing in the household.If the mother was not present, someone who knew the child answered the questions.

The third questionnaire was the **Ten Questions with Probes (TQP)**, which was the instrument for screening disabilities in the children (**Appendix 3**). This questionnaire contains ten main questions plus probe questions that follow each of the main questions. The ten main questions were tested previously in the International Pilot Study of Severe Childhood Disability (Belmont, 1986) and found to be sensitive for detecting serious disability, especially severe mental retardation, but also to generate excess false positives. The purpose of the probe questions was to distinguish children who were truly disabled among all those with reported problems to the ten main questions. The usefulness of the probe questions is currently being analysed in the three countries.

The questions on the TQP are intended to be appropriate and useful for detecting disabilities in virtually all cultures, and for all children between two and nine years. (Note that for Question 9, however, which asks about the childs' speech, different versions have been prepared for two-year-olds and for three- to nine-year-olds). In addition to being simple, the TQP has special features which enhances its external validity. First, the questions are kept at a very general level, dealing with universals of human behaviour rather than culturally acquired habits, and asked in a conversational manner. Secondly, the informant is asked to compare the child to other children of the same age within the community. Being thus 'internally standardised', the instrument has the flexibility to be used in many different cultures and countries.

Each of the questionnaires used in Stage I was translated into the local dialect of the community and administered verbatim.

Stage II : All children positive in the TQP and a randomly selected sample of TQP negatives (about 10%) were included in the second stage. The TQP negatives were included to determine whether there were any false negatives. Stage II was carried out within two weeks of the screening whereby a team of professionals (physicians and psychologists) did a comprehensive neurodevelopmental assessment **without knowledge of the children's screening results** (see Chapter Three for details).

For children with diagnosed disabilities, an additional form, the **Rehabilitation Form,** was completed by the psychologist or physician. This form provides information about the child's treatment history; current needs for treatment, special education or rehabilitation; and whether resources were available to the child for meeting those needs.

Community Description Form : To provide information about the community surveyed for use in interpreting the results from the screening and evaluations, and for planning services, a Community Description Form was completed by the project director. On this form was noted information about the community characteristics such as facilities for health care and education, the role of the child in the economy, social attitudes towards disability, and whether there were substantial numbers of homeless children in the community.

Data Management : With the exception of the Community Description Form, which was largely open-ended and descriptive, all of the survey and clinical forms were structured and pre-coded in a near-uniform manner. The data were then entered from the written forms into computer data base files.

3.3.Initial Results:

Data analysis is currently being done in all three countries in collaboration with The Sergievsky Center, Columbia University, U.S.A.

Initial results (**Table 2.3**), from site 1 ie Dhaka city, show the TQP to be a sensitive

Table 2.3 : Estimates of the Validity of the Ten Questions for Screening Serious Disabilities, and Estimates of Prevalence of Serious Disability in Dhaka (based on the subsample of 359 children referred for clinical evaluation)

	All children	Boys	Girls	Older children (5-9 years)	Younger children (2-4 years)
Sensitivity:	1.00	1.00	1.00	1.00	1.00
Specificity:	0.95	0.94	0.96	0.94	0.95
Positive predictive value:	0.22	0.20	0.26	0.23	0.21
Negative predictive value:	1.00	1.00	1.00	1.00	1.00
Prevalence (per 1000):	16	17	15	17	12

From: Zaman et al, 1990. Validity of the 'Ten Questions' for Screening Serious Childhood Disability: Results from Urban Bangladesh. I J Epid 19, 3:618.

screen for moderate to severe disability in two- to nine-year-old children, but that most children who screen positive are not severely or moderately disabled (Zaman et al, 1990). With a positive predictive value of only 22%, the TQP cannot function well on its own as a case-finding tool for epidemiologic studies of serious disability or as a basis for referring children for rehabilitation services. The fact that no cases of serious disability were missed, however, supports the conclusion that the TQP does function well as a screening tool when, as in this study, all children screened positive are referred for more definitive evaluations. Although TPQ produces many false positives, it still reduces the number of children to be evaluated by professionals from 100% to only about 7% (ie. the percentage with one or more problems reported on the TQP).

Initial results reported from Bangladesh and Pakistan also indicate that the questionnaires have a fair to excellent reliability (Durkin et al 1989).

3.4. Discussion:

From the results obtained so far, the TQP seems to be a sensitive and reliable method for screening two- to nine-year-old children for serious disability by community workers.

Eventually, it will be possible in future studies to refer only those children with positive screening results to Stage II to be evaluated more definitively by professionals. However, until the validity of the TQP is well documented, it is recommended that in all studies a sample of children with negative TQP results be included in the second stage to determine whether there are any false negatives. For such studies, the clinical evaluations should be done within two weeks of the screening and the clinicians should do the examination without knowledge of the child's screening results.

4. Conclusion:

The REA study formed the basis of the field work for this thesis. This chapter discussed both conceptual issues regarding methodology and selection of priority areas for the study of childhood disabilities in developing countries, and also presented some initial findings of the REA study. In the succeeding chapters, reference will be made to this study in various contexts.

CHAPTER THREE

The study design, methods and materials (Part A)

Introduction

Part A of the study hoped to verify the first two specific aims, which were stated in Section 10 of Chapter One. This chapter describes the study design, and the methods and matarials used. The population on whom it was conducted are described, along with some of their general health characteristics, which was expected to be reflected on their disability status. Computing and data analysis are discussed in the final sections.

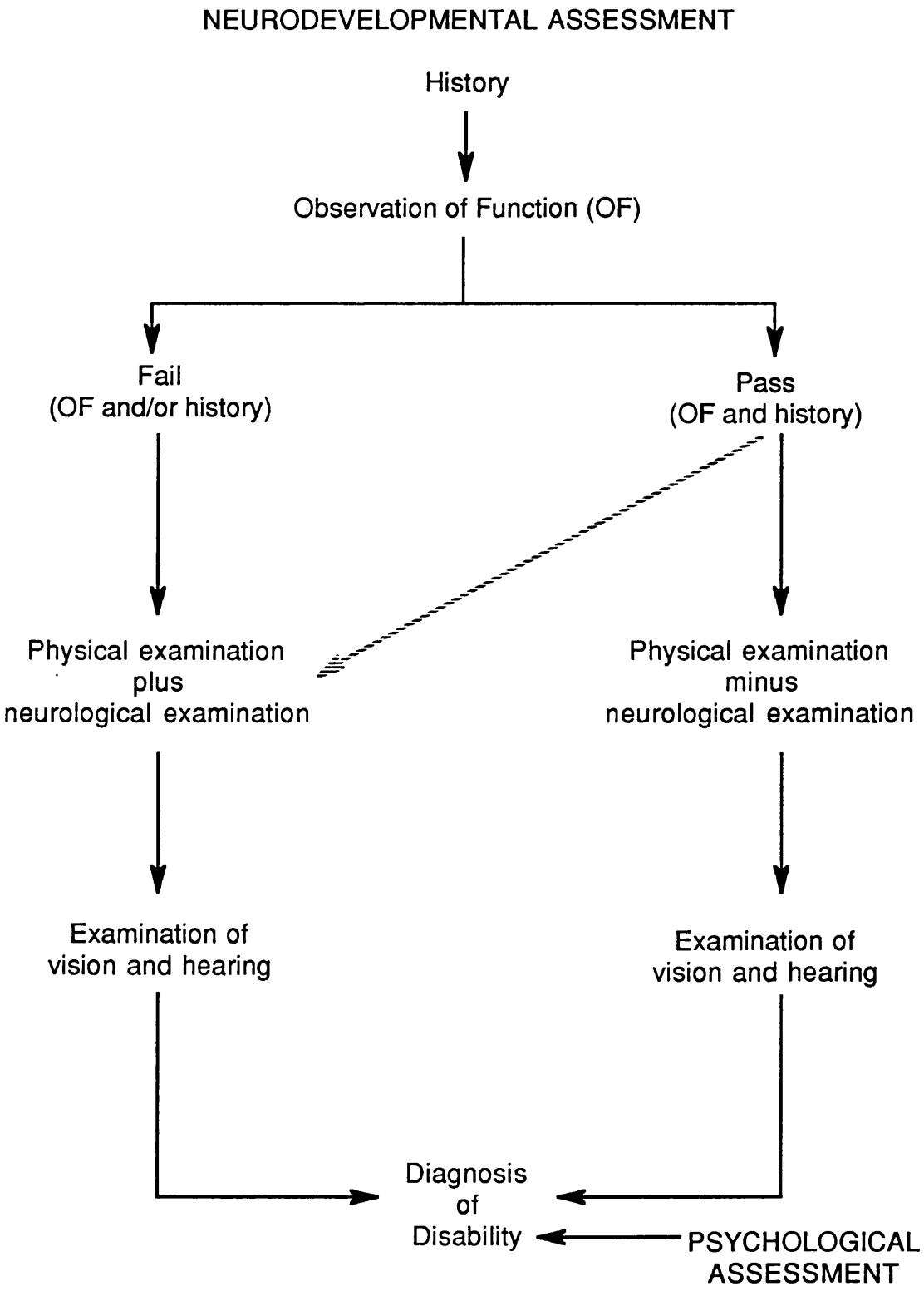
1. The study design:

A procedure called the 'Observation of Function' (OF) was developed to be used within the context of neurodevelopmental assessments done by physicians. The procedure was brief, and scored by observing the child perform a simple set of tasks. The accuracy (or validity) of the test was ascertained by comparing its results with those of the final diagnosis of the child. That is, the final diagnosis served as the 'gold standard' for the test (Fletcher et al, 1988). This was possible due to the sequential format of the neurodevelopmental assessment and is shown in **Fig.3.1.** The entire assessment was carried out by the same person. At the end of each assessment the examiner was asked *not* to go back and change the scoring on the OF, even if further examination had revealed more about the child's functions.

The subjects of the study consisted of all the children in the REA study who were brought in for professional evaluation (Chapter Two, Section 3.2.3). This group included all those who were screen - positive (ie. were at risk of having a disability) and a proportion who were screen - negative (ie. were at risk of having a disability), who served as controls. The professionals were unaware of the screened status of the child.

Every child was given (a) a neurodevelopmental assessment, and (b) a psychological assessment. Neurodevelopmenal assessments (NDA) were made in order to ascertain disabilities of movement, hearing, vision, speech, comprehension and epilepsy. The OF was an

Fig. 3.1 : The study design.



addition to the NDA, and was conducted on all children after completing the history and before beginning the physical examination.

After the physical examination, two selected groups of children received the neurological examination. These were the children who had failed the OF, or had a positive history for developmental problems, and a group of children who had passed both the history and the OF, and who served as controls.

Examination of vision and hearing was conducted for all children. The input from the psychological assessment was made at the diagnostic stage, ie. at the end of each examination, when both psychologists and physicians discussed the child in question and came to a consensus. At the end of each NDA, children were diagnosed for impairments and disability in the respective domains.

2.The study proforma- the Medical Assessment Form:

The neurodevelopmental examination of each child was recorded in the **Medical Assessment Form (MAF) (Appendix 4)**. The chronological order of the sections within the MAF were as follows:

1.The History

2.Observation of Function

3.Physical Examination

4.Neurological Examination

5.Anthropometry

6.Vision and Hearing

7.Summary Sheet

2.1.History:

A comprehensive **medical and developmental history** of the child's problems was elicited from the person who had brought the child for the examination, usually the mother.

Concerns about the child's walking and hand functions, hearing, vision, speech, seizures and learning problems and any other major health problem were enquired about specifically. In the case of a positive response, approximate age at onset, events associated with the problem, treatment received if any, and family history of having similar problems were noted.

History of parental **consanguinity** was recorded.

As **seizure** phenomenon could only be diagnosed by careful and detailed history, special care was taken to record any history of provoked and unprovoked fits, character and frequency of fits, and treatment(s) received, if any.

Mother's obstetric history, and the **child's perinatal history**, were recorded, with special emphasis on antenatal care, place of birth, by whom delivered, birth asphyxia (how soon did the infant cry after birth?), size of baby and neonatal problems. The **nutritional history** included duration of breast feeding, and child's age if and when bottle feeding was started.

Milestones were recorded for three aspects of development: age when the child walked without help; age when the child used one single word with meaning; age when the child put two or three words together meaningfully.

Immunisation status was recorded on DPT, BCG and polio vaccination. History of **past illnessess** was asked about, including accidents and injuries; any incidents with loss of consciousness; and common infectious problems, especially measles, diarrhoea/dehydration and tuberculosis.

A few questions about the child's **behaviour** were asked, ie. is he withdrawn or shy? Is he aggressive? Does he have odd repetitive movements? Are there any other concerns regarding behaviour?

At the end of the history-taking section, the examiner recorded whether he or she thought the informant had given an accurate history.

2.2. The 'Observation of Function':

The 'Observation of Function' (OF) was done on all children in the study. Each child was asked to perform a few functional tasks in a very informal manner and was rated on the observations made. Materials used for the test were familiar to the child and can be purchased in any local village shop.

All children were asked to perform the same set and sequence of tasks. Ratings of 'function' were based on the examiner's experience of age-appropriate functions of normal and disabled children. It was thus 'internally standardised'. The entire test took about one minute to complete.

2.2.1.Steps of the test:

A large spacious area was chosen for the test. Usually it was in the courtyard of a typical Bangladeshi village homestead (**Fig. 3.2.**) or a space where the child could walk at least five steps.

Without the knowledge of the child the examiner placed a coloured bead (8mm.diameter)

Fig. 3.2 : A typical courtyard

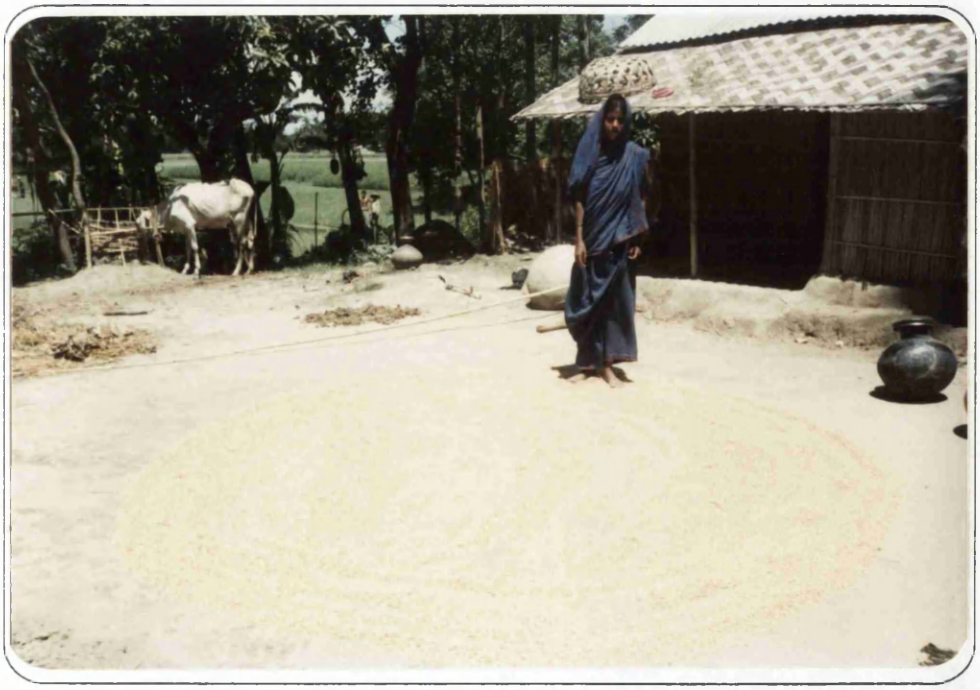


Fig.3.3. : Observing the child pick up the bead and the coin from the floor

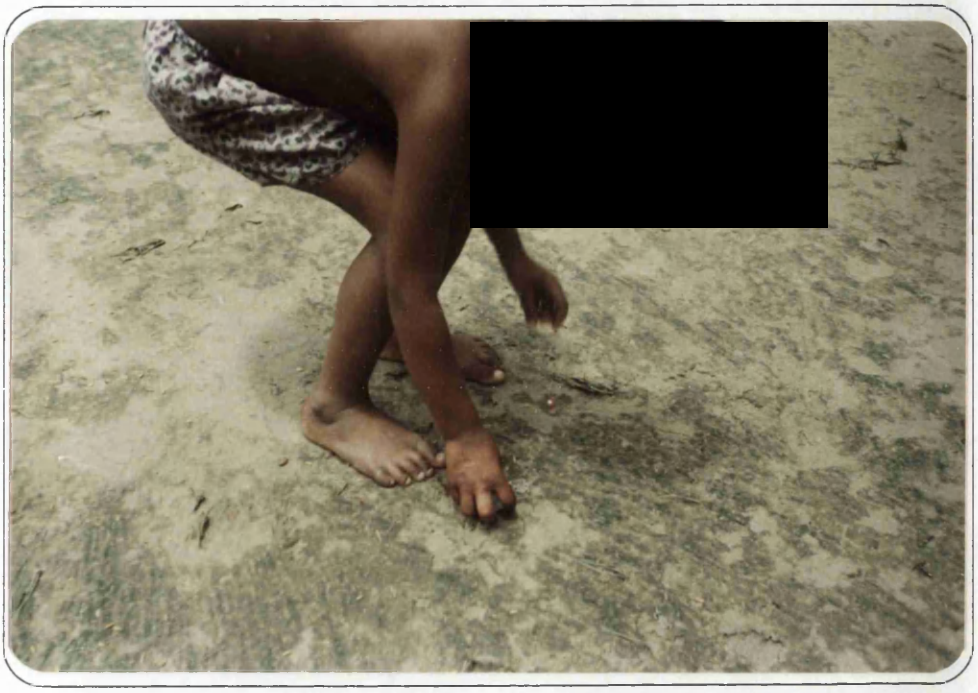
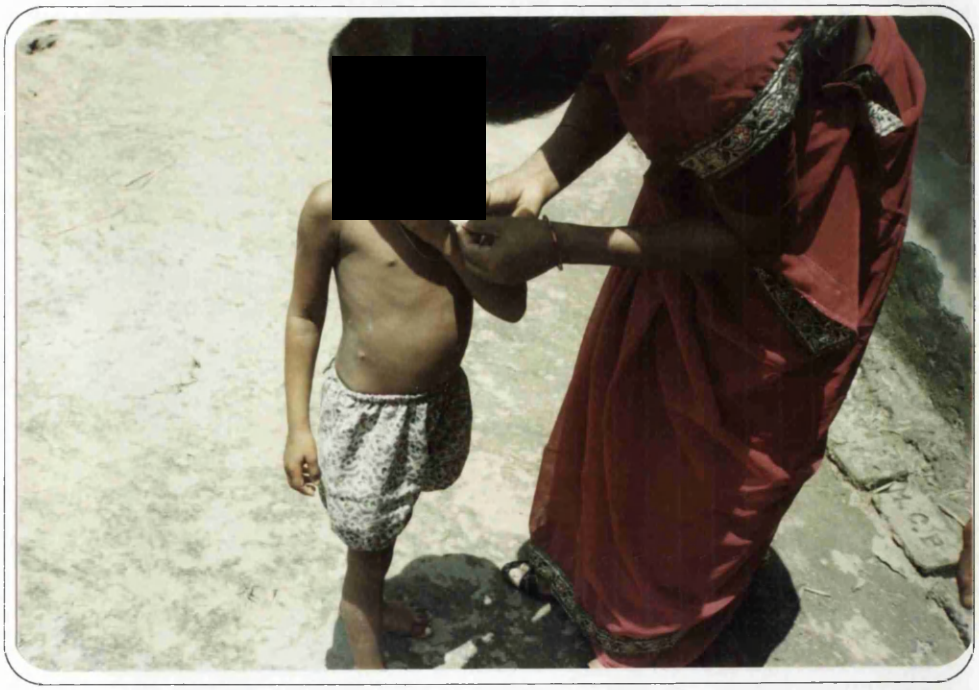


Fig.3.4. : Eliciting a verbal response



and a coin (Bangladesh 10 paisa, which is slightly larger than an old five pence coin in diameter) on the floor, at a distance of about five metres from the child.

He/she was then asked if there was anything on the floor, and if so to pick them up and give them to the examiner or the mother (ie., if the child was shy or too young or afraid of strangers) (**Fig. 3.3.**). The examiner made sure that the instruction was only verbal and the exact location of the object was not given away by gesturing.

The child was then asked 'What did you pick up?' (**Fig. 3.4.**) 'What is that?' (pointing to a chair, mat, pot etc.) 'What is this called?' (pointing to nose, ear, foot, etc.). The examiner tried to elicit a spoken answer by these questions.

Next, the child was asked to identify a few body parts (eg. 'Where is your hair?', 'Which is your right leg?', 'Can you show me which hand you eat with?').

The examiner then took a paper and pencil and drew a shape and asked the child to make an identical one (scribble for a two-year-olds, circle for three-year-olds, square for four- to six-year-olds, and diamond for seven- to nine-year olds). This was done at the back of the MAF.

2.2.2 Functions observed by the test:

As the child walked towards the bead (at least five or six paces) the examiner was asked to observe the presence or absence of gait problems, assymetry, unsteadiness, toe walking, ataxia, involuntary movements or any other problems of gross motor function and mobility. Overt signs of muscle wasting, deformities or contracture were also noted.

As the child located the objects on the floor, walked towards them, squatted and picked them up, a combination of several functions was observed. These are: gross motor functions of squatting and standing up from squatting (proximal muscle weakness); the observer was asked to notice whether the child uses hands to get to the upright position; fine motor functions of asymmetry of grasp, fisting, absence of pincer grasp and quality of grasp were observed. Difficulty in locating the objects or groping for them were additional points of observable

visuo-motor function.

The child's response was noted to the observer's verbal requests and questions, that required both verbal and non-verbal responses. Apparent problems of hearing, speech and comprehension were looked for. These functions were also observed as the child pointed to the various body parts.

When the child was drawing on paper, eye-hand coordination and fine motor abilities were observed. As many of the children would not have received any formal education, this part of the test was given relatively less weight, and judged on the basis of each child's educational exposure.

All through the test the response and alertness of the child to the observer, mother and surroundings were observed. For example, the examiner asked him or herself: does this child hear, make an appropriate social response, smile, act shy, understand and speak in an age-appropriate manner.

2.2.3 Scoring of the 'Observation of Function':

The examiner summarised the observations by scoring the child in each of the seven functional domains of development, ie. gross motor, fine motor, hearing, vision, speech (articulation), speech (language), and comprehension. As mentioned earlier, the age-appropriateness of the task was always kept in mind.

Scores for **gross and fine motor** functions were based on well-recognised patterns of abnormality, that clinicians are trained to detect (Touwen, 1979; Sutherland, 1984). **Vision and hearing** were scored from the visual and listening behaviour of the child, such as hesitancy, repetition of instruction in a louder voice by the examiner, searching for the object, groping etc (Sonksen, 1984). **Speech** score was based on any articulatory difficulty given the child's age (Bishop and Rosenbloom, 1987). **Language** score was dependant on the understanding of verbal commands and questions asked. **Comprehension** scores depended more upon how the more Piagetian qualities of 'reaching' out for the object (prehension) and

'giving' it to someone (release) was acheived, as well as naming objects with the proper 'labels'(Holt, 1991). The scorings were categorical:

'Pass' if no functional abnormalities had been detected.It meant that the child accomplished the tasks without showing overt abnormalities in that particular function.

'Fail' if there were definite observable difficulties in accomplishing the task, attributable to that functional domain.

'Uncertain' if the observer could not determine with certainty whether the child could carry out the function.

'No response' if the child did not attempt to do the task.

The policy was to have as few 'no responses' as possible. Since the tasks involved were not unusual and did not use anything foreign to the child, as well as being done in the child's environment with the mother present, it was assumed that not many children would be scored in this category. For even the two-year-olds, the tasks were well within their repertoire of functions (Illingworth, 1987).

The rating of 'Uncertain' was used when the examiner was not perfectly sure of a definite problem existing. Children falling into this category could either be on the milder end of the disability spectrum or normal children with abilities masked by shyness, etc.

2.2.4. An overall rating based on the mother's history and 'Observation of Function':

Before going on to the physical examination the examiner was asked whether he or she thought that the child needed a neurological examination based on a probable motor, hearing, vision, or cognitive impairment. For this question the examiner was asked to take into consideration the medical history ascertained from the mother, and the performance of the child on the 'Observation of Function'. The response was either 'Yes', 'No', or 'Uncertain'. The examiner was instructed not to change the answer to this question later, ie. after finishing the physical examination.

2.3. The physical examination:

This part comprised the general physical examination with special emphasis on the child's general appearance (wasting, malnourished) and dysmorphic features of the face, eyes, ears, limbs, etc. It also included an auroscopic examination of the ears; examination of the eyes especially for Vitamin A deficiency, squint, nystagmus, odd-looking eyes and a fundoscopic examination; examination of the neck for goitre; examination of the chest and abdomen; testes in males ; limbs and hands for signs of wasting, deformities, contractures, missing limbs, etc.

For the classification of xerophthalmia (Vitamin A deficiency) and goitre (iodine deficiency disorder), the child was graded according to internationally accepted classifications (Sommer, 1982; Delange and Dunn, 1987).

At the end of this part of the MAF the examiner wss again asked whether he or she thought the child needed a neurological examination, answering either 'Yes' or 'No'.

2.4. The neurological examination:

Many aspects of the traditional neurological examination were included in the general section. This section mainly concentrated on the neuromotor system.

The child was examined for **mobility** (which was recorded on a graded scale of 1 to 8 , ranging from 'normal gait' = 1, to 'ambulant with aids, limited' = 4, to 'not ambulant,bedridden' = 7, to 'uncertain' = 8).

Manual dexterity was assessed for both hands and recorded on a scale ranging from 'slight impairment' to 'marked impairment' to 'no useful function'.

Floppiness and **scissoring** were recorded.

Muscle tone was ascertained in all four limbs and recorded. **Tendon reflexes** were seen for biceps, triceps, supinator, knee and ankle. **Plantar** responses were recorded.

Involuntary movements, instability, ataxia, and titubations were recorded.

Proximal and distal **muscle weaknessess** were tested.

A **sensory examination** was carried out only when indicated (eg. in case of a spinal level

of a motor deficit, peripheral neuropathy, etc.).

2.5.Examination of vision, hearing and speech:

Visual acuity of three- to nine-year-olds was examined with the Sheridan-Gardiner Picture Chart or the Landholt C-Chart, depending on the presumed mental age of the child. Where this was not possible and in all two-year-olds, the 'fix and follow' test was used, using graded beads (Sonksen, 1983). Recordings were made for each eye.

Hearing was examined by a screening audiometer in three- to nine-year-olds, whenever possible (**Fig. 3.5.**). In cases where the child had a mental or chronological age of below three years or felt intimidated by the audiometry apparatus, the Performance Test (three- to five-year-olds), the Co-operative Test (one- to two-year-olds) or the Distraction Test (below one year) was used (McCormick, 1988).

Fig. 3.5. : Testing hearing with a screening audiometer

Speech was elicited by asking the child to describe a picture which was of a river with a boat and cows grazing in the far-off fields. It was done in a conversational manner. Problems of both receptive and expressive language were ascertained. When the examination of vision had not been possible in any child using the methods described earlier, the boat-picture was placed at a distance of about six metres and the same questions asked, thus testing vision as well. This procedure seemed analogous to the Ladybird picture-cards used by Sonksen and Macrae (1987).

2.6. Anthropometry:

Each child's weight was recorded on a weighing scale in kilograms. Height was recorded on a stadiometer in centimetres. Where the child could not stand, a supine length board was used. The head circumference and upper mid-arm circumfernce (UMAC) was recorded in centimetres with a measuring tape. The mother's height, weight and head circumference were similarly recorded.

2.7.The summary sheet:

This was the final section of the medical evaluation. The examiner scored the child on ten areas of development and physical health for impairment, diagnosis (specific disease entity where it existed), disability, and treatment needs. The problems covered were: **gross motor, fine motor, hearing, vision, speech, seizures, cognition, psychiatric, nutritional** and **other health problems.**

Disabilities were distinguished from impairments based on the functional abilities of the child given the underlying organic impairment. For example, a child with post-polio paresis of the lower limb, ie. an impairment due to an organic cause, could have difficulty in ambulation, ie. a disability as the function of walking was hampered. The guidelines outlined by the World Health Organisation for impairments and disabilities were adapted for this purpose (WHO, 1980b). The adaptations that were made to suit the study design and constraints are discussed

in the next section.

For cognitive problems, two separate decisions were made. First, the examiner made a recording of his or her decision, independent of the **psychologist's assessment** results. These were based on standardised tests as well as tests derived from ecological inventories (Munir, 1990). Then a **consensual decision** was made on the basis of a discussion between the physician and the psychologist. More emphasis was given at this point to the psychologist's opinion of the child's cognitive abilities and performance on the psychological tests.

Disabilities were graded as 'none', 'mild', 'moderate', 'severe', or 'uncertain', according to predefined criteria (cf. next section).

Wherever possible, the International Classification of Diseases (WHO, 1977) was used to record the codes for the diseases or problem entities.

2.8. Case definition of disability:

In the definition of cases, the classification proposed by the World Health Organization (1980b) was adhered to as far as was feasible. The severity of disability rating, as well as the associated symptoms is given in a comprehensive form in **table 3.1**. A serious case of any disability was recorded for any child receiving a disability rating of either three or four (indicating a moderate or severe disability) in the Summary Sheet of the MAF for either gross motor, fine motor, hearing, vision, speech, seizure or cognition (joint decision).

To be considered as having **serious movement disability**, the child would at best be unable to use hands for implements and/or able to move only with substantial help. A child who had a **mild movement disability** may have a weak grasp, or a diminished use of pincer grasp, but be able to use hands for all other purposes such as eating, writing etc., and be able to walk without help, but may need help in climbing steps. The diagnosis of movement disorders was obtained through the history and the observation of function, as well as the neurological examination.

A child with **serious hearing disability** was one with more than 40db hearing loss (or

Table 3.1: Severity Rating for the Disabilities during the Medical Assessment.
(WHO, 1980; Procedure Manual, 1987)
Rating of 2 = mild, 3 = moderate, 4 = severe

Movement	
Mild:	weak grasp, can use hands for most purposes, can stand without support, may need help in climbing steep steps.
Moderate:	difficulty in holding implements, dressing, needs support to sit upright, can move around with substantial help.
Severe:	unable to walk, no functional use of hands except to point.
Hearing	
Mild:	a 26 to 40 Db loss of hearing in the best ear, difficulty in hearing, but able to manage with or without a hearing aid.
Moderate:	a 41 to 70 Db loss in the best ear, difficulty in hearing even with a hearing aid.
Severe	more than 70 Db loss in the best ear, no useful hearing.
Vision	
Mild:	can see the chart through a pin-hole, correctable vision loss.
Moderate:	vision loss of 20/60 feet or 6/18 m, not correctable, but can get about with a cane.
Severe:	visual acuity worse than 6/60, only light perception.
Seizure	
Mild:	two to four seizures in the past year.
Moderate:	more than one seizure per month.
Severe:	more than one seizure per week.
Speech	
Mild:	speaks and is understood, but can get across only basic ideas.
Moderate:	understood with difficulty, gets only basic needs across.
Severe:	either no speech, or cannot be understood by others.
Cognition	
Mild:	slow in cognition, no accompanying motor, speech deficit or delay in milestones.
Moderate:	some delay in attaining growth milestones, difficulty in speech as well as moderate cognitive deficit.
Severe:	with fine motor deficits, delay in speech and in attaining growth milestones, as well as with a significant cognitive deficit.

Severity rating for Mental Retardation on Psychological Assessment

The information on Adaptive Behaviour Scale, Psychological Tests (Binet or DDST), revised CDQ, and the Examiner's observation of the child's behaviour help to determine the mental retardation. The psychologists then classify children as 'normal', 'at risk', 'moderately retarded' and 'severely retarded'. The final diagnosis on mental retardation is based on a consensus decision involving MDs and psychologists.

20db above the background noise). A child with **mild hearing disability** had less than 40db loss and had difficulty responding to sounds. All these applied to the better ear. Where pure tone audiometry could not be done, the hearing/ listening behaviour of the child was graded.

A child with a **serious vision disability** was one who had worse than 6/18 visual acuity in the better eye.

Speech disability was regarded as a separate disability in the present study. The child was asked to name objects and describe a picture of a rural riverside scene. Otherwise diagnosis of speech problems, mainly expressive speech, was done by the examiner through the history, observation of function, and physical examination. To be considered as having a **serious speech disability**, the child would at best speak with difficulty and communicate basic needs. A child with **mild speech disability** was able to speak and be understood,but could get only basic ideas across.

During the medical assessment, **cognitive disability** was assessed through history, observation of function, physical examination and neurological examination, examination of vision and hearing. A child with mild mental retardation would be only slow in cognition. A child with moderate mental retardation would have some delay in attaining major milestones, probably difficulty in speech, as well as a moderate cognitive deficit. A child with severe mental retardation would have a high possibility of global delay, with fine motor deficits, delay in speech as well as in attaining major milestones of development, and significant cognitive deficits. Both the moderate and the severe cases comprised **serious cognitive disability**.

Seizure disability was the only disorder where no information except maternal history was available to the physician to verify a case. The report given by the informant in the section on history was considered authoritative. As illustrated in table 3.1, to be considered as having a **serious seizure disability**, the child had to have had more than one seizure per month. For **mild seizure disability**, the frequency of seizures had to be more than two times in the past year.

3. Training of physicians to use the 'Observation of Function':

Training of the physicians to perform the observation and to assess children appropriately was very important, especially as this was a departure from the standard history and physical examination. In practice, the items are all found in tests used to evaluate children with motor or psychological problems. Nevertheless, the supervision of a paediatric neurologist or developmental specialist would have been useful. In the absence of a trained specialist, the study physicians evaluated children with known problems, to compare their own diagnosis (using the 'Observation of Function' and the MAF) to those done by the standard diagnostic work-up in use at the academic centre.

One paediatrician (N.K) and one physician (E.R., with two years' work experience in paediatrics in the Dhaka Shishu Children's Hospital) were involved in the field work. N.K. had been involved with the study from the planning stages in developing the Medical Assessment Form and the 'Observation of Function'. Both physicians practised the entire Medical Assessment Form including the OF in 'Kalyani', a child development clinic in Dhaka city, two months before the actual field work started. Twenty-five of these examinations were validated by a consultant paediatrician, with good correlations. No normally functioning children were seen, although it had been suggested in the planning stages of the work. No formal tests of validity were done. Though the field situation could not be simulated, the physicians felt confident about using the OF after this exercise.

4. The Study Population:

It has been mentioned in the study design that all children who were professionally assessed in the REA project comprised the study population. **A total of 1626 children from the five study sites were included.** For the purpose of analysing the usefulness of the OF in identifying disabilities, it was decided that all children from all sites would be considered together. This was presuming a degree of uniformity of test situations, problems observed, and examiners doing the testing. It was decided to look for discrepancies by site,

gender, age, etc. at a later point during the analysis.

4.1. Age and sex distribution:

Table 3.2 shows a slight preponderance of boys in all the study sites. Extra efforts were made to keep refusal rates to a minimum. Community workers went to each key homestead to convince the mothers to bring their child(ren) for evaluation. In several cases the professional team went to houses to see children with non-compliant parents. For these reasons it can be assumed that the slight male preponderance is incidental, and not the result of the male children getting preferance for the time of the parents. In one of the urban sites (Dhaka) no major gender or age differences were detected in validity of the TQP (Zaman et al, 1990).

Table3.2 : Study Population by Age and Sex Distribution in the Five Study Sites.

	Sites						
Age	1 Dhaka M/F	2 Dhamrai M/F	3 Barisal M/F	4 Kurigram M/F	5 Chittagong M/F	Total M/F	Grand Total
2	22/15	14/17	20/16	7/11	25/24	88/83	171
3	17/25	20/21	14/10	9/12	19/33	79/101	180
4	19/19	31/30	16/18	11/1	18/9	95/77	172
5	26/18	38/18	21/25	17/11	19/16	121/88	209
6	31/25	28/18	17/11	7/6	34/19	117/79	196
7	27/25	56/35	29/19	14/18	42/27	168/124	292
8	25/22	34/21	17/14	8/8	23/21	107/86	193
9	20/23	31/22	22/6	15/8	41/25	129/84	213
Total	187/172	252/182	156/119	88/75	221/174	904/722	1626

4.2. TQP status:

As explained in Chapter 2, all these children were screened by the TQP for probable disability. **Table 3.3** shows the TQ status of the children by the five sites. The overall percentage of positivity was 46% (range 40.3% to 49.3%). This meant that although almost half of the children were at high risk for disability, a substantial proportion were also presumably normal. This strengthened the rationale using the OF for trying to identify and screen out normally functioning children so that their impaired counterparts could receive a more thorough examination.

Table 3.3 : Study Population by Study Sites and TQ Positivity.

Sites	Children Seen	TQ Positive	%TQ Positive
1	359	157	43.7
2	434	214	49.3
3	275	133	48.3
4	163	66	40.3
5	395	170	43.0
Total	1626	740	45.5

4.3. Basic health parameters:

The disease-impairment-disability-handicap spectrum has been discussed in Section 2. Background information on some relevant factors in the primary health care of the children was essential to form any ideas on the patterns of disability emerging and scope for prevention, treatment and rehabilitation. **Table 3.4.** gives a profile of some of these parameters by urban (site 1 and site 5) and rural (sites 2, 3 and 4) groups. Given the centralised healthcare system in Bangladesh, discussed in Chapter One, urban populations have more access to health care facilities, and it was thought that this would be reflected in some of the parameters highlighted

Table 3.4 : Background Information on Some Relevant Primary Health Care (PHC) Statistics of the Study Children Divided into Urban and Rural Groups and Expressed as Percentage of Total Population (Urban = 754, Rural - 872).

PHC Parameter	Urban	Rural
Consanguinity		
None	81	88
1st cousin	10	8
Distant relative	4	3
Unknown	5	1
Total	100	100
Antenatal care		
None	64	82
Yes	21	5
Unknown	15	13
Total	100	100
Place of birth		
Home	80	97
Clinic/birthing centre	8	1
Hospital	4	-
Unknown	8	2
Total	100	100
Born at term?		
Yes	82	88
>1 month early	3	2
>2 weeks late	1	1
Unknown	14	9
Total	100	100
Delivery assisted by		
Trained midwife/TBA	12	5
Untrained TBA/dai	55	58
Relative/other	11	25
Doctor	8	1
Unknown	14	11
Total	100	100
Size of baby at birth		
Average	60	77
Smaller	13	7
Bigger	9	1
Unknown	18	15
Total	100	100

Contd.

Table 3.4. : continued.

	Urban	Rural
Breast fed		
Never	5	4
<1 month	4	1
1 - 6 months	9	6
7 - 12 months	10	10
13 - 24 months	34	18
>24 months	23	52
Unknown	15	9
Total	100	100
Bottle fed		
Never	32	42
From <1 month	21	19
From 1 - 6 months	18	18
From 7 - 12 months	9	7
From 13 ->= 24 months	6	4
Unknown	14	10
Total	100	100
Solids introduced		
3 - 6 months	12	5
7 - 12 months	11	5
>12 months	63	82
Unknown	14	8
Total	100	100
Polio vaccination		
Complete	14	6
Incomplete	6	5
Not given	65	79
Unknown	15	10
Total	100	100
DPT vaccination		
Complete	16	6
Incomplete	8	6
Not given	62	78
Unknown	14	10
Total	100	100
BCG vaccination		
Given	22	18
Not given	66	77
Unknown	12	5
Total	100	100

in the two groups. All the information was taken from the MAF.

The data from this table indicate that although urban children were slightly better served as regards antenatal care of their mothers, delivery by trained midwives and vaccine status, they were poorer in the nutritional parameters that lead to better health, eg. breast feeding. Discussion on the socio-demographic variables that lead to a poorer health status of inner city mobile populations living in slum dwellings is beyond the scope of this study. It is however important to acknowledge such factors for the sake of a better understanding of the types of impairments and disability across this group.

Thus it can be said that majority of the study children had not received antenatal care; were delivered by untrained TBAs or relatives; had poor nutritional history, the majority having started on regular family food after two years (their breast feeding status was however commendable, as it prevents a number of infections in infancy and childhood); and substantial numbers were not vaccinated. This made them more susceptible to specific (eg. Vitamin A deficiency) and general (eg. marasmus, protein-energy malnutrition) nutritional problems, infections (eg. polio, diphtheria) and non-specific developmental delay.

5. Data computing:

All forms used were coded and computed on the software program DBase Three Plus. The analysis was done by translating the data into the SPSS PC Version 3.1. The Wordstar release 5.5 was used for word processing.

6. Analysis:

The order of the analysis was as follows:

6.1.The descriptive data :

This was carried out in order to see the types, distributions and severities of disabilities within the study population, as well as to see the scoring patterns on the OF. Frequency tables

were used.

6.2. The reliability of the OF:

To measure the reliability of the OF, a proportion of the children were re-examined either by the same examiner, or by another examiner, at an interval of two weeks. Presuming that the disability status of the children had not changed within this time interval, the ratings on the OF on both occasions were compared. The **Kappa Co-efficient**, a statistical technique to interjudge agreement for nominal scales, which takes into account the agreement beyond chance, was used to determine both inter- and intra-observer agreement (Cohen, 1960; Longstreth, 1987). Guidelines for interpretation are given in **Table 3.5.**.

Table 3.5. : Guidelines for interpretation of Kappa Statistics[a].

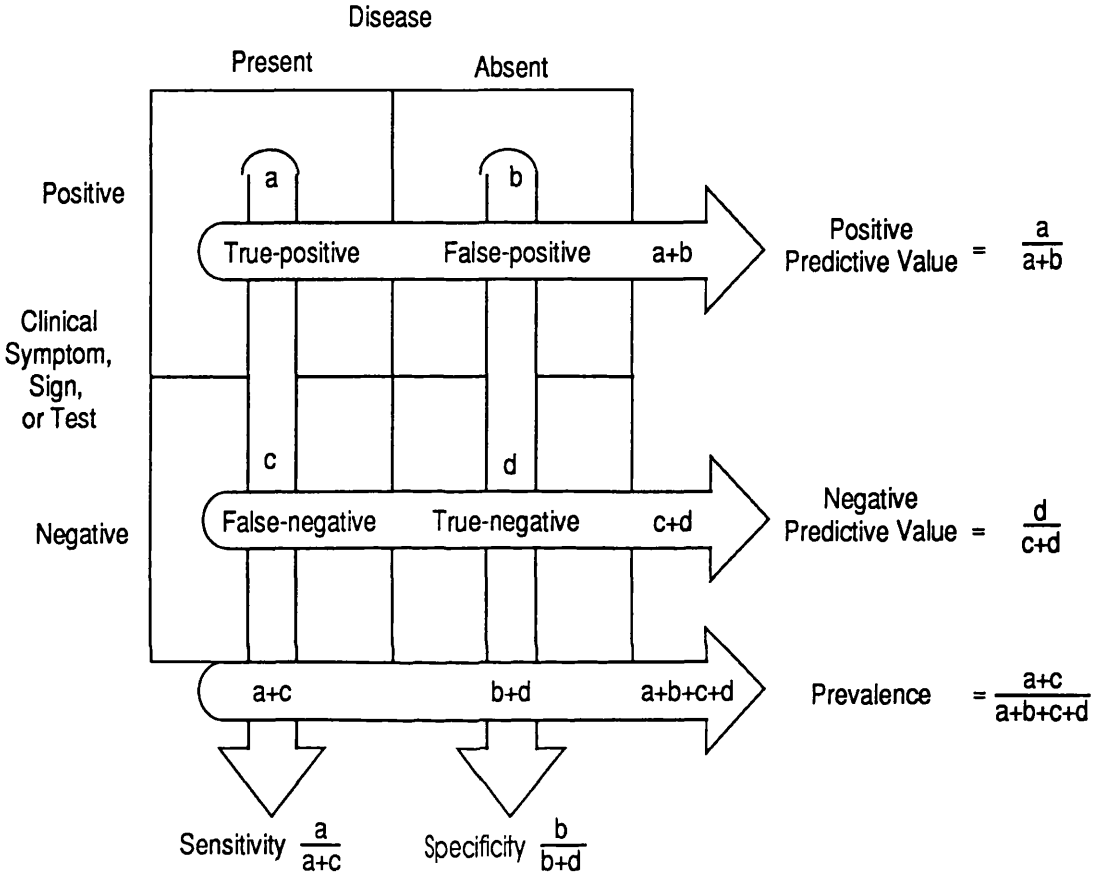
Kappa Statistic	Agreement
0 to .2	Slight
.2 to .4	Fair
.4 to .6	Moderate
.6 to .8	Substantial
.8 to 1.0	Almost perfect

[a]From : Landis JR, Koch GG : Measurement of observer agreement for categorical data. Biometrics 1977;33 : 159-174.

6.3.The validity of the OF expressed as sensitivity and specificity :

The validity is how well some measure relates to the diagnosis of interest.**Sensitivity** and **specificity** are validity measures that are independant of the prevalence of the condition (Ades,1990). These measures served the purpose of the study very well as the study population

Fig 3.6. : Characteristics and definitions of diagnostic symptoms, signs and tests. Modified from works by Fletcher and associates and Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, Ontario. Letters (a,b,c and d) represent specific number of patients categorized by disease status and presence or absence of some symptom, sign ot test result.



From : Longstreth et al, 1987

was derived from five different sites. Sensitivity and specificity (cf. Section 2) are **calculated from each of the four cells of a four-fold table obtained from cross-tabulating the outcome of the measure (in this case: scores on the OF) with that of a criterion measure or 'gold standard' (in this case: diagnosis of disability).** When both the test and the criterion agree, the cells are called True Positive (Negative). When the test is positive but the criterion is negative, the cell is called False Positive. When the test is negative but the criterion is positive, the cell is called False Negative. Calculation of sensitivity (the proportion of true positive cases correctly identified by the test) and the specificity (the proportion of true negative cases correctly identified by the test) is shown in **Fig. 3.6**. For each value, the 95% confidence interval is given to show the degree of variability (Gardiner and Altman, 1986).

6.4. The homogeneity of the sensitivity and specificity scores of the OF:

Homogeneity of rates and proportions (in true positives and true negatives) may be analysed using non-parametric tests that compute a chi-square statistic based on the difference between the observed and expected frequencies (Armitage and Berry, 1987). By default, equal frequencies are expected in each category. Probability results display significant differences and demonstrate test bias.

The independant variables that were seen to be important potential sources of bias were age, gender, and study sites, and were the used for this part of the analysis.

6.5. Accuracy of the mother's history:

This analysis was done to see how well mothers identified disability (including severity). Variables from the history were compared with the 'gold standard' of disability outcome, and expressed in terms of the sensitivity and specificity.

6.6. The yield of the OF when combined with the mother's history:

The yield of a test may be measured according to predefined criteria. In screening tests it is used to 'measure the number of cases identified whose prognosis is improved with early detection' (Rose and Barker, 1978). In this study it was used to answer three questions: (a) How much more was gained by the physician using the test, *over and above the mother's history*? (b) How much did it strengthen the information gained from the history? (c) Did the gains, if any, save a suffient amount of working time? (Rose mentions that any yield has to be balanced against costs, ie. staff, time, facilities, etc.).

6.7. The predictive value of the OF:

The probability of disease, given the results of a test, is called the predictive value of the test. Positive predictive value is the probability of disease in a person with a positive (abnormal) test result. Negative predictive value is the probability of not having the disease when the test result is negative (normal) (Fletcher, Fletcher and Wagner, 1988). Calculations of predictive values are given in Fig. 3.6.. These are properties of a test dependant on the prevalence of the condition being measured, and results will vary with the kind of population the test is examining (Ades, 1990).

The study population was comprised of children who were either at high risk for disability (TQP positive) or normal (TQP negative). For this part of the analysis, only children who were **TQP positive** were considered, as they would have the highest likelihood (prevalence) of disability. They were also the population on whom neurodevelopmental assessments were most likely to be done. However, to see whether the predictive values were similar for the **TQP negative** group, values were calculated correcting for the proportion of the entire screened population (10,300 children) represented by this group (TQP negative) in the study.

6.8. Analysis related to the second aim of the study:

The purpose was to verify whether the OF could be used in lieu of the neurological examination in those children identified as functionally normal.

Children were divided into categories according to their status on (a) mother's history and OF, and (b) whether neurological examination was done or not. Disabilities in the different categories were tabulated.

Two categories of children were identified, as **cases** (all children who failed the OF and/or the mother's history), and **controls** (a randomly selected group of children who passed the mother's history and the OF) (Schesselman, 1982). Differences in neurological outcomes were noted within and between these two groups to ascertain (a) how these signs affected disability outcome and definitive diagnosis, and (b) how many controls were neurologically impaired, to ascertain whether the study design missed children with neurological impairment.

7. Time duration of the field work and data analysis:

The field work of the study was done from mid-1987 till mid-1988. Field and office editing of the data was done as part of the main REA study in Dhaka city. Further editing and analysis of the data was done between 1990 and 1991 at The Wolfson Centre, Institute of Child Health. A substantial part of 1989 (seven months) was spent in doing the field work for Part B of this study (Chapter Six).

CHAPTER FOUR

Results (Part A)

Introduction

The results of Part A of the study are presented according to the analysis plan described in Chapter Three, Section 6. The order of presentation of the results is listed below:

(1) Descriptive data.

(2) Reliability of the OF.

(3) Sensitivity and specificity of the OF.

(4) Homogeneity of the sensitivity and specificity results across study sites, genders and age groups.

(5) Accuracy of the mother's history.

(6) Combined yield of the mother's history and the OF.

(7) The predictive values of the OF.

(8) Analysis of cases and controls for the neurological examination.

1.Descriptive Data :

In Section 4 of the previous chapter the characteristics of the study population by age and sex distribution, similarities across study sites (ie. urban versus rural) of basic health parameters, and TQP status, have been described. As mentioned, the main analysis was done by amalgamating children from all five study sites, and discrepancies between them were looked for seperately.

This section provides background information on the frequencies and grades of the different categories of disabilities found in the study children. The information is important insofar as it represents the problems that the OF was required to identify, ie. the 'gold standards' against which the validity of the OF was measured.

Table 4.1 shows the distribution of the specific types of disabilities found in the study population by severity and percentage of total disabilities. Moderate and severe grades are

Table 4.1: Distribution of Specific Disabilities by their Severities and Expressed as Numbers of Children and Percentages of the Total Disabilities.

Type of Disability	Severity of Disability				Total	
	mild		moderate/severe			
	n	%	n	%	n	%
Motor	23	5.5	35	8.4	58	13.9
Hearing	51	12.2	24	5.8	75	18.0
Vision	34	8.1	17	4.1	51	12.2
Speech	36	8.6	85	20.4	121	29.0
Cognition	47	11.3	46	11.0	93	22.3
Epilepsy	16	3.8	3	0.7	19	4.6
Total	207[a]	49.6	210[b]	50.3	417[c]	100

[a]207 types of disabilities in 112 children

[b]210 types of disabilities in 142 children (see also table 4.4)

[c]417 types of disabilities in 284 children (see also table 4.3)

grouped together (cf. Chapter Two, Section 2.6). It can be seen that 17% of the study population (284 out of 1626 children) had a disability, and that many of them had more than one problem (417 kinds of disabilities were found amongst the 284 disabled children).

There were almost equal number of children in the mild and moderate-to-severe (serious) categories of disability. This could have a reflection of the main REA study, where the screening questionnaire was shown to be more sensitive to serious disabilities (Chapter Two, Section 3). Serious grades of disabilities are less prone to any influence by psycho-social and environmental factors (Alberman, 1984). However, in underprivileged societies and social groups, a tendency for milder problems to regress to serious categories has been seen (Stein, 1986); a tendency that tends to reverse in more developed communities (Hagberg, 1981).

Given all the problems of testing children in field situations for less defined conditions such as mild mental retardation (MMR), it was thought that serious categories were a more stable reflection of the disabilities in this study. Another explanation is derived from the information in Table 4.2.

In **Table 4.2.** the distribution of the study population for impairments (inclusive of most

Table 4.2 : Distribution of Types of Impairments (inclusive of most disabilities) in the Study Children Expressed as Number of Children and as Percentages of Total Impairments.

Impairment	Number of Children	%
Motor	64	9.7
Hearing	115	17.5
Vision	219	33.2
Speech	132	20.0
Cognition	108	16.4
Epilepsy	21	3.2
Total	659[a]	100

[a]659 impairments were found in a total of 475 children

disabilities due to ascertainable organic causes) is shown. Almost 30% of the children (659 out of 1626) had some form of impairment, a sharp rise over disabilities. This was seen as a reflection of the poor general health status of the children. The gray areas which often exist between impairment and milder forms of disability especially in developing countries may also be evidenced from this. There was also a tendency for physicians to label, treat and alleviate any form of impairment, rather than stigmatise a child for disability, however mild. This was especially so for conditions such as ear infections causing mild hearing deficits, xerosis of the eye causing night blindness or generally poor health and marasmus showing as apathy and lack of alertness and cognitive skills in a child. In developing countries, the mildly disabled population may blend with the normal population, as expectations are less demanding. Based

upon these rationales, decisions for grouping children into broader categories was taken, and is explained below.

Decisions for further analysis derived from Table 4.1 and Table 4.2: The tables indicated that there was an under-representation of the mild forms of disabilities in the study population, and questioned the validity of considering it as a separate group. It was therefore decided that for all further analysis two categories of children would be considered. These were: (a) 'all' disabilities, comprising all categories of severity of disability, and (b) 'serious' disabilities, comprising those grouped in the moderate and severe categories.

For additional qualitative information regarding the neurodevelopmental outcome of the disabled children, the reader is referred to **Appendix 5** (for all grades of disability) and **Appendix 6** (for serious grades of disability). Clinical diagnosis of disabled children is given. Similarities and differences can be seen at a glance by looking at each study site. The diagnostic groupings were not taken from the ICD-9 codes, but from the written text in each child's file. They are the kinds of 'working' diagnoses that physicians write into case-notes, but most are also well-recognised diagnostic categories (Drillien and Drummond, 1983). Crude prevalence rates were also calculated. Reference to these two appendices will be made in succeeding sections where required.

Two more descriptive tables are given in this section. They show the distribution by age groups of all the disabilities found, in the 'all' and 'serious' categories respectively. In **Table 4.3** all grades of disability by age distribution are shown. From the distribution it is seen that over one-fourth (ie. 155) of all disabilities were found among the two- to three-year-olds. Of these the majority were speech and motor problems. This indicated that perhaps there was an over-diagnosis of these problems in the younger age group, where many of these children could be at the extreme end of normal development. The policy to include them in the disability category was also based on longitudinal studies which have shown that a substantial proportion of children with speech and/or motor delay in the early years, go on to have problems in later life (Drillien and Drummond, 1983; Richmond, Stevenson and Graham, 1982). The table also

Table 4.3 : Distribution of all grades and types of disabilities in the study population stratified by age and expressed as the frequencies of disabilities in each category.

	Disabilities						
Age	Motor	Hearing	Vision	Speech	Cognition	Epilepsy	Total
2	22	2	4	61	15	1	105
3	11	2	3	19	11	4	50
4	3	2	2	5	6	-	18
5	6	7	4	9	11	5	42
6	5	7	9	4	8	2	35
7	1	18	11	10	15	2	57
8	6	21	4	7	15	1	54
9	4	16	14	6	12	4	56
Total:	58	75	51	121	93	19	417

shows a clustering of vision and hearing problems in the children aged seven years and above. Cognitive disabilities and epilepsy were evenly spread out in all age groups.

The distribution of the 210 'serious' disabilities in the various age groups is shown in **Table 4.4.** 103 (75+28) two- and three-year-olds had serious disabilities, reflecting a similar picture to that seen in the previous table. The majority of these had speech (46+12=58) and motor (18+8=26) problems. Again, vision and hearing disabilities were found amongst the

Table 4.4 : Distribution of the 210 types of serious disabilities stratified by age in the study children and expressed as the frequencies of disabilities in each category.

	Serious disabilities						
Age	Motor	Hearing	Vision	Speech	Cognition	Epilepsy	Total
2	18	1	2	46	8	-	75
3	8	1	-	12	6	1	28
4	1	1	-	3	2	-	7
5	3	2	1	7	7	1	21
6	3	3	2	4	6	1	19
7	-	4	4	6	8	-	22
8	1	7	-	4	5	-	17
9	1	5	8	3	4	-	21
Total:	35	24	17	85	46	3	210

older group, and cognition and epilepsy were evenly spread out. Only three children had 'serious' epilepsy.

Decisions for further analysis derived from Table 4.3. and Table 4.4: It was decided that all age categories would be considered together for the analysis, despite clustering of age groups around certain disabilities. It seemed that diagnosis had been more lenient for younger children but was not so dissimilar to trends seen in other studies, where the largest type of problem found was speech disability, followed by global delay (Drillien and Drummond, 1983). This was, however, a caveat to heed in the interpretation of results.

Decisions made on the scores of the OF to be used in analysis: The initial distribution of the frequency tables and crosstabulations (not given here as tables) of the OF scores revealed certain traits, based upon which decisions were made for analysis. The trends revealed and the consequent decisions made are enumerated below:

(a) There was no difference between children who scored 'uncertain' and 'no response' from those who scored 'fail' in terms of their disability outcomes, which was evenly spread. Based on this distribution, the two former scores were collapsed with the latter, so that a child either 'failed' or 'passed' in each of the seven domains, ie gross motor, fine motor, hearing, vision, speech (motor), speech (language) and comprehension. Scores from each domain will be referred to as the function-specific score.

(b) Scores on the gross motor and fine motor functions were combined to form a single 'motor' score. The speech (language) score was combined with the comprehension score to form a single 'comprehension' score.

(b) An overall score was derived, based upon whether the child 'passed' or 'failed' on any one or more of the seven function-specific scores.

2. The reliability of the OF:

Intra-observer reliability tests were done on 68 children and inter-observer tests on 20 children. In each of these, the results of the function-specific scores and overall score of the OF

Table 4.5 : The Intra-observer Reliability Co-efficients (actual and kappa) for the OF scores based on repeat assessments of 68 children.

	Reliability Coefficients	
OF score	actual	Kappa
Motor	.98	.97
Hearing	1.00	1.00
Vision	1.00	1.00
Speech	1.00	1.00
Comprehension	1.00	1.00
Overall score	.92	.65

was compared between observer/observation one and observer/observation two. The reliability co-efficients were expressed as 'actual' and 'kappa' co-efficients (cf. Chapter 3, Section 6.2.).

The intra-observer reliability: In 68 children the assessment was repeated by the same examiner at an interval of two weeks. **Table 4.5.** shows the reliability scores. The kappa co-efficients (*k*) was almost perfect for motor (fine and gross), hearing, vision, speech (motor), speech (language) and comprehension , ie. all the function-specific scores. The lower bounds of the 95% confidence intervals were also within this range.

k was substantial for the overall score (.65).The lower bounds of the 95% confidence interval was in the moderate range.

The inter-observer reliability: The inter-observer rating on the OF by the two examiners on 20 children was calculated and is given in **table 4.6.** Whilst the actual reliability co-efficients were very good for all items, they were reduced considerably when corrected for chance, ie. *k*. This was substantial for the motor (gross and fine) scores (.64), although the lower bounds of the 95% confidence interval was in the moderate range. It was almost perfect for the hearing and vision scores.It was moderate and fair on the speech (.47) and comprehension (.31) scores respectively. The overall score was in the moderate range, with the

Table 4.6 : The Inter-observer Reliability Co-efficients for the OF scores based on repeat assessments by two examiners of 20 children.

	Reliability Coefficients	
OF score	actual	Kappa
Motor	.95	.64
Hearing	1.00	1.00
Vision	1.00	1.00
Speech	.90	.47
Comprehension	.85	.31
Overall score	.89	.42

lower bounds of the 95% confidence interval going down to fair. A caveat to interpreting these scores lies in the fact that the numbers were probably to small, and tests of larger samples need to be done for greater accuracy.

3.Results on the sensitivity and specificity of the OF:

This section presents the sensitivity and specificity of the OF to identify the various disabilities described in section one. It is organised into two sub-sections. The first sub-section looks at the overall score of the test, and how well it identified (a) disabilities in general (b) motor disability specifically, and (c) all other disabilities (including motor disabilities, for comparison) in a summary table. The second sub-section looks at its usefulness when the function-specific scores of the OF were considered to identify the respective individual disabilities.

Children with **epilepsy per se** and no other disability were excluded from this analysis, as this was not a functionally observable phenomenon, the diagnosis of which was based upon history only. This meant that out of the 284 children with some form of disability (Table 4.1), 14 children who filled this criterion were excluded, resulting in the analysis of 270 children. Similarly, amongst the serious disabilities, two children were excluded, resulting in the analysis of 140 children.

Table 4.7 : Cell frequencies and sensitivity and specificity of the overall score of the OF to identify (a) all disability, and (b) serious disability.

(a)

		all disability		
		present	absent	
Overall score on the OF	fail	121	27	148
	pass	149	1329	1478
		270	1356	1626

sensitivity= .44 (95% C. I. = .38 - .50)
specificity = .98 (95% C. I. = .97 - .99)

(b)

		serious disability		
		present	absent	
Overall score on the OF	fail	102	46	148
	pass	38	1440	1478
		140	1486	1626

sensitivity= .72 (95% C. I. = .65 - .79)
specificity = .96 (95% C. I. = .95 - .97)

For practical reasons, all the sensitivity and specificity results (including the 95% confidence limits) are tabled as point estimates, but discussed as percentages in the text.

3.1. The sensitivity and specificity of the overall score of the OF to identify disability:

In **table 4.7.** the cell frequencies of the two four-fold tables compared the dichotomous outcomes on the overall score of the OF (fail or pass) with the dichotomous outcomes of (a) all disability (present or absent) and (b) serious disability (present or absent).

Table 4.7(a) shows that 121 children were correctly identified by the **OF (overall score)** to have a **disability**, giving a sensitivity of 44% (with lower bounds of the 95% C.I. at 38%). 27 children were falsely categorised as disabled out of a total of 1356 normal children, giving specificity of 98%.

The sensitivity improved when the score was crosstabulated with children who had **serious disability (table 4.7(b))**, without a significant loss of specificity (96%). Of the 102 **true positives**, 83 had speech problems, 48 cognitive disability, 41 motor disability, 17 hearing disability, eight vision, and one child with epilepsy. All these occurred in various combinations, so that 40% of them had isolated problems, and the rest had two or more disabilities in various combinations. Of the 83 children with some degree of **speech disability**, the single largest problem identified, 52% (43 children) were two-year-olds. One third of the 83 children had single speech problems, of which 78.6% (22 children) were again in the younger age group. All 13 children identified for **hearing disability** had perceptive deafness and all except one child had other associated problems, mainly mental retardation diagnosed in five, and speech delays in 11. This also included one child who was blind. Of the other four children diagnosed for **vision disability**, two were blind and two children had corneal opacity that occluded vision. The children with **motor disabilities** are discussed in the following section.

Out of the 38 children who were not identified by the test (ie. **false negatives**), 27 had a

single disability. Of these eight had serious mental retardation (SMR), six had hearing defects (four conductive deafness and two perceptive), 10 had problems of vision (five diagnosed as seriously disabled in vision due to poor visual acuity tests, five with eye changes due to xerophthalmia), and three with speech delays. Of the 11 children who had more than one disability, nine had some degree of MR (six had SMR), including one blind child. Two children had speech and hearing defects. **None of them had motor disabilities.**

3.2. The sensitivity and specificity of the overall score of the OF to identify motor disability:

The cell frequencies in the two four-fold tables in **table 4.8.** compared the outcome of the overall score of the OF with the diagnosis of (a) all motor disabilities, and (b) serious motor disability.

To compare the overall score, which included seven developmental domains, with the diagnosis of a specific disability (ie. motor) might include many more false positives. However, it was thought that a failure in any of the other domains might be due to an underlying motor problem. For example, a child with mild cerebral palsy could manifest functionally as delayed in speech development, or slow in comprehension.

Forty-five children (**true positives**) out of a total of 58 with **motor disabilities**, were identified by the overall score of the OF (**Table 4.8(a)**). Of these, 35 were seriously motor disabled children and their diagnostic details are discussed with the next table. The remaining 10 children were the ones with mild motor disabilities. Six had other associated problems of MR and speech delay associated with a diagnosis of motor developmental delay. Of the four children with isolated mild motor disability, three had post-polio paresis and one had a thigh abscess.

Out of the 13 children who were missed by the test (**false negatives**), three had talipes, three had post-polio lameness, two had developmental motor delay, and the other five had one of the following each as their diagnosis: Erb's palsy, facial palsy, mild cerebral palsy,

Table 4.8 : Cell frequencies and sensitivity and specificity of the overall score of the OF to identify (a) all motor disability, and (b) serious motor disability.

(a)

		all motor disability		
		present	absent	
Overall score on the OF	fail	45	103	148
	pass	13	1465	1478
		58	1568	1626

sensitivity= .77 (95% C. I. = .65 - .89)
specificity = .93 (95% C. I. = .92 - .94)

(b)

		serious motor disability		
		present	absent	
Overall score on the OF	fail	35	113	148
	pass	0	1478	1478
		35	1591	1626

sensitivity= 1.00 (95% C. I. = .90 - 1.00)
specificity = .93 (95% C. I. = .92 - .94)

odd-looking facies (with perceptive deafness and speech problems), and high arched foot. Eleven out of the 13 false negatives were over three years of age.

All 35 children who had serious motor disability were identified (**true positives**) as shown in **table 4.8(b).** The diagnosis of their problems were the following: 16 had developmental motor delay, nine had cerebral palsy, four had post polio lameness, two had flat foot, one had ricketts and one had club-foot. Six out of the total 35 children had isolated motor problems, of which three were post-polio lameness, one was dislocated shoulder joint, one was a club-foot, and one child was diagnosed as 'flat-foot'. Seventeen out of 35 children (ie. 49%) were two years of age. Another three were three-year-olds.

The number of false positives was 113, giving a specificity of 93% for the test. The specificity increased (thus reducing the number of false positives) when the motor function-specific score was considered, without lowering the 100% sensitivity. This is discussed in the next section when all function-specific scores of the OF are considered.

3.3. The sensitivity and specificity of the overall score of the OF to indentify other disabilities:

Similar to the previous tables, the overall OF score was compared with the diagnosis of motor, hearing, vision, speech and cognitive disabilities respectively.

The sensitivities and specificities were calculated and are given in a summary form in **table 4.9.** Specificity was high, rangeing from 91% for hearing and vision problems, 93% for motor and cognitive problems and 96% for speech disabilities. The confidence intervals were also narrow. However sensitivity was not as uniform. It was poor for vision and hearing, better for cognition, and best for motor and speech. For vision, hearing and cognitive disabilities, the lower bounds of the 95% confidence for the sensitivity scores were very low.

The sensitivities improved when disabilities of the serious categories were considered only and is given in **table 4.9(b).** This included more than half (54%) of all serious hearing disabilities; over three-quarters (76%) of serious cognitive disabilities; 92% all serious speech

Table 4.9 : Summary of the Sensitivity and Specificity of the overall score of the OF to identify specific disabilities in the (a) all, and (b) serious categories.

	(a) all				(b) serious			
Disability	Se	95% CI	Sp	95% CI	Se	95% CI	Sp	95% CI
Motor	.77	.65 - .89	.93	.92 - .94	1.00	.90 - 1.0	.93	.92 - .94
Hearing	.24	.15 - .33	.91	.90 - .92	.54	.34 - .74	.91	.90 - .92
Vision	.21	.01 - .32	.91	.90 - .92	.29	.07 - .51	.91	.90 - .92
Speech	.73	.68 - .84	.96	.95 - .97	.92	.86 - .96	.95	.94 - .96
Cognition	.54	.44 - .65	.93	.92 - .94	.76	.64 - .88	.92	.91 - .93

disabilities; and 100% of all serious motor disabilities (also seen in Section 3.2). There was no significant fall in specificity scores. However,lower bounds of the 95% confidence interval have to be considered,especially for serious hearing problems, for which the sensitivity fell to 34%.

3.4.The sensitivity and specificity of the function specific scores of the OF to identify the individual disabilities:

Each score of the OF in the seven functional domains was calculated as a dichotomous variable of 'pass' and 'fail' and crosstabulated with dichotomous outcomes on the diagnosis of respective disabilities. As mentioned earlier, the fine motor and gross motor scores were fused into one motor score, which was compared to a single score of motor disability; the speech (motor) was compared with speech disability; both the speech(language) score and the comprehension score was compared individually to the diagnosis of cognitive disability and expressed as cognitive disability 1 and cognitive disability 2 respectively.

The sensitivity and specificity results are given in **table 4.10**. With the exception of motor disability, all the sensitivity scores were reduced in **table 4.10** in comparison to those in the previous table. Therefore, the individual scores of the OF did not do better than the overall score to identify individual functional problems, except for motor problems. The language

Table 4.10 : Summary of the sensitivities and specificities of the individual scores of the OF in identifying specific motor, hearing, vision, speech and cognitive disabilities in the (a) all and (b) serious categories.

	(a) all				(b) serious			
Disability	Se	95% CI	Sp	±95% CI	Se	95% CI	Sp	±95% CI
Motor	.75	.64 - .86	.99	.004	1.00	.90 - 1.0	.98	.01
Hearing	.16	.08 - .24	.99	.004	.45	.25 - .65	.99	.005
Vision	.07	0 - .14	.99	.005	.23	.03 - .43	.99	.005
Speech	.41	.32 - .50	.98	.01	.50	.40 - .60	.98	.01
[a]Cognition1	..42	.32 - .52	.96	.01	.59	.45 - .73	.95	.01
[b]Cognition2	.27	.17 - .37	.98	.01	.41	.27 - .55	.98	.01

[a] 'language' score on the OF has been compared with Cognitive Disability.

[b] 'comprehension' score on the OF has been compared with Cognitive Disability.

function-specific score correlated better with the diagnosis of cognitive disability than the comprehension function-specific score.

As is evident, the specificity improved considerably in both tables. This did not have much significance except for motor disability, as because many children who were truly disabled were missed (because of the reduced sensitivity) at the cost of reducing false positives. However, for motor problems it meant that instead of recommending large numbers of children (ie. 148 children: table 4.7) for a more definitive evaluation, much fewer numbers could be recommended, without losing any child with serious motor disability and perhaps one or two with milder problems.

3.5. Conclusions from the sensitivity and specificity results:

1. 44% of all disabilities, and 72% of serious disabilities were identified by the procedure.

2. Serious disabilities were identified more accurately than the milder grades, for all types of disabilities.

3. Over three-quarters (77%) of all motor disabilities, as well as 100% of all serious motor disabilities were identified.

4. The test was more sensitive in those children who had multiple problems, especially in the hearing, MR, vision, and speech categories. Most single motor problems were identified.

5. More of the two- and three-year-olds were picked by the procedure. The majority of those who were missed were in the older age range.

6. The overall score was more sensitive than the function-specific score for identifying individual disability. The exception was serious motor disability, which did better with this score as many false positives were reduced.

4.The homogeneity of the sensitivity and specificity of the OF:

Outcomes of the test across study sites, and between genders and age groups were considered. The homogeneity of the sensitivity and specificity of the overall score of the test to identify all grades of disability, serious disability, all grades of motor disability and serious motor disability across these groups were compared. Chi-square statistics for ratio of proportions was calculated. Significant differences were expressed as the p value (cf. Section 6.4., Chapter 3).

4.1.Across study sites:

The sensitivity and specificity of the OF for any disability and serious disability by the five study sites is given in **table 4.11.** There was significant differences between each site in the sensitivity and specificity for all grades of disability ($p < .0001$). There was also significant difference in specificity for serious disability ($p < .0001$). Despite the differences, it was interesting to note that the results became more sensitive and specific form site 1 through site 5. This may have occured because of the growing efficiency and expertise of the testers to use the OF temporally.

Sensitivity for **serious disability** was homogenous across study sites ($p > .01$).

Table 4.11 : Homogeneity of the sensitivity and specificity of the OF to identify all disability and serious disability, in 5 study sites.

	all disability					serious disability				
Site	n	Se	X^2	n	Sp	X^2	n	Se	X^2	n	Sp	X^2
1	83	.36		276	.92		38	.59		321	.90	
2	66	.24		368	.99		25	.60		409	.99	
			24.91[a]			63.93[a]			10.62[b]			59.18[a]
3	34	.49		241	.99		19	.80		256	.99	
4	23	.42		140	1.0		14	.64		149	.99	
5	64	.69		331	1.0		44	.77		351	.98	

Degrees of freedom = 4

[a] $p < .0001$

[b] $p > .03$

Table 4.12 : Homogeneity of the sensitivity and specificity of the OF to identify all motor and serious motor disability, in 5 study sites.

	all motor disability					serious motor disability				
Site	n	Se	X^2	n	Sp	X^2	n	Se	X^2	n	Sp	X^2
1	11	.63		348	.86		5	1.0		352	.86	
2	14	.79		420	.98		8	1.0		426	.97	
			1.74[b]			48.9[a]			2.25[b]			43.63[a]
3	12	.83		263	.97		9	1.0		266	.96	
4	6	.67		157	.96		2	1.0		161	.95	
5	15	.87		380	.92		11	1.0		384	.91	

Degrees of freedom = 4

[a] $p < .001$

[b] $p > 0.7$

Table 4.12 shows that there was homogeneity in the sensitivity of the outcome for motor disability ($p > .01$). Specificity ($p < .0001$) showed significant differences across study sites, although again there was improvement from site 1 (86 percent) to site 5 (91%).

4.2. In boys versus girls:

Table 4.13 showed no differences in test outcome between the two sexes for disability of all severities as well as serious disabilities.

Table 4.13 : Homogeneity of the sensitivity and specificity of the overall score of the OF to identify all disability and serious disability, in boys versus girls.

	all disability					serious disability				
Site	n	Se	X^2	n	Sp X^2	n	Se	X^2	n	Sp X^2
Boys (n=904)	147	.43	0.107[a]	757	.98 1.447[a]	70	.75	0.888[a]	834	.97 0.722[a]
Girls (n=722)	123	.45		599	.97	70	.68		652	.96

[a] $p > 0.2$

Table 4.14 shows that the test was equally sensitive and specific in picking up motor disabilities of all grades of severity in boys and girls.

4.3.In younger versus older children:

Table 4.15.compared the differences in outcome on the OF in identifying disability between younger (two- to four-year-old) and older (five- to nine-year-old) children. There were significant differences between the two groups in all test outcomes. It was more sensitive and less specific in younger children. The sensitivity fell sharply in older children for all grades of

Table 4.14 : Homogeneity of the sensitivity and specificity of the overall score of the OF to identify all motor disability and serious motor disability, in boys versus girls.

	all motor disability					serious motor disability				
Site	n	Se	X^2	n	Sp X^2	n	Se	X^2	n	Sp X^2
Boys (n=904)	32	.75	0.028[a]	872	.94 1.173[a]	18	1.0	1.089[a]	886	.93 0.937[a]
Girls (n=722)	26	.76		696	.92	17	1.0		705	.92

[a] $p > 0.3$

severity (25%) and serious (49%) disability. The specificity was almost perfect for older children.

Table 4.16. indicates that the sensitivity for serious motor disability was perfect for both age groups. Specificity was lower in the younger children for all grades of disability. Sensitivity was significantly different for all disabilities found which included mild ones too. It was less in the older children, who had mild motor problems subtle enough not to be observed by the test.

4.4.Summary of the homogeneity results:

(1) The most homogeneous test outcomes between study sites was in the sensitivity for all disabilities in the serious category, and motor disability, especially serious motor disability. Significant differences were seen in the specificity for all problems.

(2) All test outcomes analysed were homogeneous between boys and girls.

(3) Younger and older children did not differ in their outcome for serious motor disability. However, they varied significantly in other validity results.

Descriptive data has already shown that the overall study diagnosed younger children for certain disabilities most frequently, mainly motor and speech. This was also seen to be

Table 4.15 : Homogeneity of the sensitivity and specificity of the overall score of the OF to identify all disability and serious disability, in younger versus older age groups.

	all disability				serious disability			
Age group	n	Se	n	Sp	n	Se	n	Sp
		X^2		X^2		X^2		X^2
Younger (n=523)	106	.73	417	.95	71	.94	452	.93
		60.01[a]		16.686[a]		35.40[a]		23.874[a]
Older (n=1103)	164	.25	939	.99	69	.49	1034	.98

[a] $p < .0001$

Table 4.16 : Homogeneity of the sensitivity and specificity of the overall score of the OF to identify all motor disability and serious motor disability, in younger versus older age groups.

	all motor disability				serious motor disability			
Age group	n	Se	n	Sp	n	Se	n	Sp
		X^2		X^2		X^2		X^2
Younger (n=523)	36	.86	487	.86	27	1.0	496	.85
		5.444[a]		52.879[b]		0.305[c]		53.680[b]
Older (n=1103)	22	.59	1081	.59	8	1.0	1095	.96

[a] $p < 0.03$

[b] $p < 0.0001$

[c] $p > 0.5$

developmentally justifiable. Therefore, for further analysis both younger and older age-groups have been considered together, with a caveat to the user/interpreter regarding the tendency.

(4) The ability of the OF to pick up serious motor disability was uniform and consistent between all the three group variables, ie. site, gender and age groups.

5.Accuracy of the mother's history :

This section analysed the mother's history to see how sensitive and specific it was in picking up disabilities. As this was the first part of the assessment in the study design, an accurate history would reflect the extent of the mother's perceptions of the child's problems as well as aid and influence the examiner in the subsequent examination, including the OF.

The term 'mother' was used in a generic sense to include all respondants during history taking (Appendix 4, page 1, m5).In fact, over 80% of the responses were given by the biological mothers.

An overall score of the mother's history, whether positive or negative in any of the worries regarding walking, using hands, hearing, vision, speech, and learning, was tabulated. This score was called 'positive history'. This variable was crosstabulated with the specific disabilities. The sensitivities and specificities are given in **table 4.17.**

The table shows that the mother's overall history was very sensitive in identifying most disabilities and off all grades of severity. Conversely, the specificity was low, ie. there were many false positives. This meant that many children who were actually not disabled would have to be seen by the examiner. To find a more accurate result, the mother's responses to questions about the individual problems (ie. walking, using hands, seeing) was crosstabulated with the respective disabilities. This is shown in **table 4.18.**

When individual worries were considered they reduced the sensitivity only slightly in the motor and speech domains but more so in the hearing, vision and cognitive domains. This indicated that problems of motor and speech functions were easily perceived by the mother as what they really were. Cognitive problems might be perceived as the child 'not hearing' or

Table 4.17 : Sensitivity and Specificity of the overall score on the mother's history to identify (a) all, and (b) serious motor, hearing, vision, speech and cognitive disabilities.

	all				serious			
Disability	Se	95% CI	Sp	95% CI	Se	95% CI	Sp	95% CI
Motor	1.00	.93 - 1.0	.61	.59 - .63	1.00	.90 - 1.0	.60	.58 - .62
Hearing	.77	.76 - .78	.60	.58 - .62	.83	.68 - .98	.59	.57 - .61
Vision	.84	.74 - .94	.60	.58 - .62	1.00	.80 - 1.0	.59	.57 - .61
Speech	.96	.93 - .99	.63	.61 - .65	.98	.95 - 1.0	.62	.60 - .64
Cognition	.92	.86 - .98	.62	.60 - .64	.97	.92 - 1.0	.60	.58 - .62
All	.87	.84 - .91	.68	.66 - .70	.95	.91 - 1.0	.64	.62 - .68

Table 4.18 : Sensitivity and Specificity of the specific worries of the mother regarding motor, hearing, vision, speech and cognitive functions, in identifying the respective disabilities in the 'all' and 'serious' categories.

	all				serious			
Disability	Se	95% CI	Sp	95% CI	Se	95% CI	Sp	95% CI
Motor	.89	.81 - .97	.98	.97 - .99	1.00	.90 - 1.0	.97	.96 - .98
Hearing	.60	.49 - .71	.85	.83 - .87	.70	.52 - .88	.83	.81 - .85
Vision	.62	.49 - .75	.89	.87 - .91	.88	.73 - 1.0	.89	.87 - .91
Speech	.91	.86 - .96	.93	.92 - .94	.97	.93 - 1.0	.91	.90 - .92
Cognition	.45	.35 - .55	.95	.94 - .96	.50	.36 - .64	.94	.93 - .95

'inattentive', or any such related behaviour. Vision problems, even serious ones, were missed, and might not be recognised in communities that are non school going and do not require reading skills for day - to - day functioning.

The specificity was high for most of the disabilities, compared to table 4.17, so that many of the false positives were excluded. However, it also included all the false negatives, ie. children who had unrecognised disability. As these are children that cannot be missed, it was thought that the overall score on the mother's history did much better in identifying problem children, even at the cost of including more false positives.

6.The combined yield of the mother's history and the OF:

In the sequential format of the assessment the mother's history was followed by the OF. This section analysed (a) how effective the OF was, when combined with the mother's history, in identifying disability, and (b) how effective was the individual score of the motor functions of the OF when combined with the worry by the mother on the motor functions, to identify motor disability.

The four sets of combinations of the test and mother's history (Set 1 = mother's history positive and OF positive; Set 2 = mother's history positive and OF negative; Set 3 = mother's history negative and OF negative; Set 4 = mother's history negative and OF negative) were cross-tabulated with the disability outcomes. Statistics computed were: sensitivity , specificity, test false positive, mother's history false positive, and extra number of children picked by test. The percentage of problems picked by each of the four sets was also calculated.

6.1. To identify disability :

Table 4.19(a). shows that Sets 1, 2 and 3 identified 89% of all problems in the study children. An extra 12% (33 children) were identified by Set 4. Neither Set 3 nor Set 4 included children with motor problems, which were identified by Sets 1 and 2. Sensitivity of the combined yield was 88%. However, specificity was only 67%. That is, large numbers of

Table 4.19 : The yield of the overall score of the mother's history and the overall score of the OF (arranged in four sets) to identify (a) all disability and (b) serious disability.

			(a) all			(b) serious		
set	Mother's history	OF	+	-	Total	+	-	Total
1	+	+	119	10	129	101	28	129
2	+	-	130	404	535	34	499	534
3	-	+	2	17	19	1	18	19
4	-	-	33	911	944	5	939	944
		Total	284	1342	1626	142	1484	1626

All Disability:

Sensitivity = .88 Specificity = .67
Test false positive = .02 Mother's history false positive = .30
Extra picked by test = .04
Set 1 = identified 42%
Set 2 = identified 46%
Set 3 = identified 1% (1 speech, 1 vision)
Set 4 = identified 12% (17 hearing, 7 vision, 6 cognitive, 2 speech)

Serious Disability:

Sensitivity = .95 Specificity = .63
Test false positive = .03 Mother's history false positive = .33
Extra picked by test = .03
Set 1 = identified 71.1%
Set 2 = identified 23.9%
Set 3 = identified 0.7% (1 mod. speech)
Set 4 = identified 3.5% (4 mod. hearing, 1 mod. M.R)

children would be required to get a thorough evaluation to wean out the true positives. Only two children were picked by the OF who were not positive on the mother's history.

Table **4.19(b)** shows that Sets 1, 2, and 3 identified 96% of the children. The best combination was Set 1, which identified 71% of the problems and had very few false positives (28 children). Comparatively, Set 2 had 24% positives but 499 false positives. All children with serious motor problems were included in Set 1. The sensitivity was 95%.

The difficulty at this point was the inclusion of large numbers of false positives. The specificity was only 63%. False positives on the mother's history was 33%, whilst on the OF it was 3% only.

6.2. Combination of function-specific scores to identify motor disability:

The mother's worry about walking and/or using hands was combined to form one variable called 'motor problems'. Results from this score was combined with the motor scores on the OF, to determine the yield.

Table 4.20 .shows that with the combination of the two abovementioned variables the sensitivity was 94% and 100% for all motor disabilities and serious motor disabilities respectively. Specificity was 97% (39 false positives) and 96% (59 false positives) for all grades and serious grades respectively. False positives were reduced considerably compared to the previous table.

Set 1 identified 71% (all grades) and 100% (serious grades) of motor disability, with only 1 and 7 false positives respectively. Sets 2 and 3 identified another 24% (14 cases) of the mildly disabled with 38 more false positives. Three mildly disabled children were identified by Set 4, who were one five-year-old and two eight-year-olds respectively.

It should be noted that the test alone (Set 3) picked up only 5% of children in the mild motor category over and above the mother's history. They were two two-year-olds, and one three-year-old. The diagnosis of mild motor disability for a child with thigh abscess is questionable. The physicians must have thought that labelling the child as disabled would

Table 4.20 : The yield of the 'motor history' (fine and gross) combined with the 'motor score' on the OF (arranged in four sets) to identify (a) all and (b) serious motor disability.

		motor score	(a) all motor			(b) serious motor		
set	motor history	OF	+	-	Total	+	-	Total
1	+	+	41	1	42	35	7	42
2	+	-	11	29	40	0	40	40
3	-	+	3	9	12	0	12	12
4	-	-	3	1529	1532	0	1532	1532
		Total	58	1568	1626	35	1591	1626

All Motor Disability:

Sensitivity = .94 Specificity = .97

Test false positive = .006 Mother's history false positive = .01

Extra picked by test = .05

Set 1 = identified 71%

Set 2 = identified 19%

Set 3 = identified 5% (2 global delay, 1 thigh abcess)

Set 4 = identified 5% (1 odd facies, global delay and perceptive deafness, 1 global delay, 1 facial palsy)

Serious Motor Disability:

Sensitivity = 1.00 Specificity = .97

Test false positive = .01 Mother's history false positive = .025

Extra picked by test = 0

Set 1 = identified 100%

increase her chances of receiving help, pre-empting further complications such as osteomyelitis or septicaemia. The mother alone (Set 2) picked up 19% (11 children). Of these, three had talipes, four had polio, one had Erb's palsy, one had motor delay, one nine-year-old girl had high arched foot, and one child (whose tendon jerks were brisk on the neurological examination) had a possible cerebral palsy.

There were less false positives in Set 2 than in Set 3.

6.3. Conclusions on the combined yield— calculation of time saved:

If Set 4 children were omitted from the detailed neurological examination, (given the time for each neurological examination to be around 10 minutes), 114 hours or 19 working days (given a six-hour work day) would have been saved of the physician's time during field-work. This could be utilised in the detailed examination of more impaired children.

Still more time (ie. 43 working days) might have been saved had the first three sets of combinations in table 4.20 been considered.

7. The predictive values of the OF :

The predictive values of the procedure were calculated on two populations of children. The first population comprised of all children who were TQP positive in the REA study (cf. Section 6.7., Chapter 3). **Table 4.21.** shows the results for (a)the overall score of the OF for identifying disability in general (inc. serious grades), and motor disability specifically (inc. serious grades), and (b) the function specific scores to identify motor disability.

The negative predictive values (NPV) were high in group (a) for motor disabilities, indicating that almost all children who passed on the overall score of the OF would not have a motor functional motor problems. The NPV was also high in group (b). The positive predictive value (PPV) was high in (a) for disability in general and motor disability, and also in (b) for motor disability. That is, a high percentage of all children who failed the test were expected to have a motor disability of any grade of severity. PPV for serious grades of disability were

Table 4.21 : The positive predictive value (PPV) and negative predictive value (NPV) of: (a) the overall OF score to identify all disability, serious disability, all motor disability and serious motor disability; and (b) the function specific score of the OF to identify all and serious motor disability, in the TQP positive population (n = 740).

	(a)			(b)	
	PPV	NPV		PPV	NPV
all disability	.90	.83	all motor	.93	.98
serious disability	.77	.94			
all motor	.93	.98	serious motor	.73	.99
serious motor	.73	.99			

Table 4.22 : The positive predictive value (PPV) and negative predictive value (NPV) of: (a) the overall OF score to identify all disability, serious disability, all motor disability and serious motor disability; and (b) the function specific score of the OF to identify all and serious motor disability, corrected for proportions of TQP negatives represented in the study population[a].

	(a)			(b)	
	PPV	NPV		PPV	NPV
all disability	.63	.92	all motor	.39	.99
serious disability	.49	.99			
all motor	.10	.99	serious motor	.32	.99
serious motor	.09	1.00			

[a]See appendix 7

lower, indicating that all children who failed would have to have a more detailed examination to confirm the screening.

In **Table 4.22**, the predictive values were calculated for all the study children (ie. including the TQ negatives) with a reconstructed table corrected for the entire 10,300 children who were the base population of the REA study. The PPV was much lower in this calculation for all categories of children. The reason for this was that the prevalence of disability, and specifically motor disability, is much lower in the general population, compared to a screened population. It

is a known fact that PPV declines with decreasing prevalence rates. For practical purposes it meant that if the procedure were to be used at the screening stage, only a small percentage who failed would actually have a disability. Therefore, all of them would need a definitive assessment for diagnosis. The NPV was cosistently high, indicating that it could be said with a high degree of certainty that almost all who passed the test would not have a disability.

The implications of the data from **table 4.22** are important for the last aim of the study which was to see whether the OF could be used as a valid procedure by community workers in the screening stages to enhance the screening result. This issue is dealt with in Chapter Six.

8.The neurological examination:

The second aim of the study was to ascertain whether the neurological examination as defined in the study protocol could be excluded in those children who passed the history and/or the OF. This section presents the analysis.

8.1.Categories of children :

The study design required all children who failed the OF and/or the mother's history, receive a neurological examination (ie. 542 children). To act as controls to verify whether children would be missed by omitting the neurological, a proportion of those who passed (ie. 459 children) were also examined (indicated in **Fig. 4.1**). However, as the study progressed, the examiners felt more confident about the OF, and in the later stages 140 children who failed the mother's history (of which 13 also failed the OF) did not get the neurological examination. A total of 1001 children recieved the neurological examination and 625 did not.

The summary of the distribution of children according to their status on the OF scores and neurological exaimination is given in **table 4.23**. The children were divided into four main groups (A,B,C and D). Group A were children (542) who either failed the test and/or the mother's history and received the neurological examination. Group B were children (140) similar in status to Group A, but who did not receive the neurological examination. 944

Fig. 4.1 : Numbers of children examined in the different stages of the study.

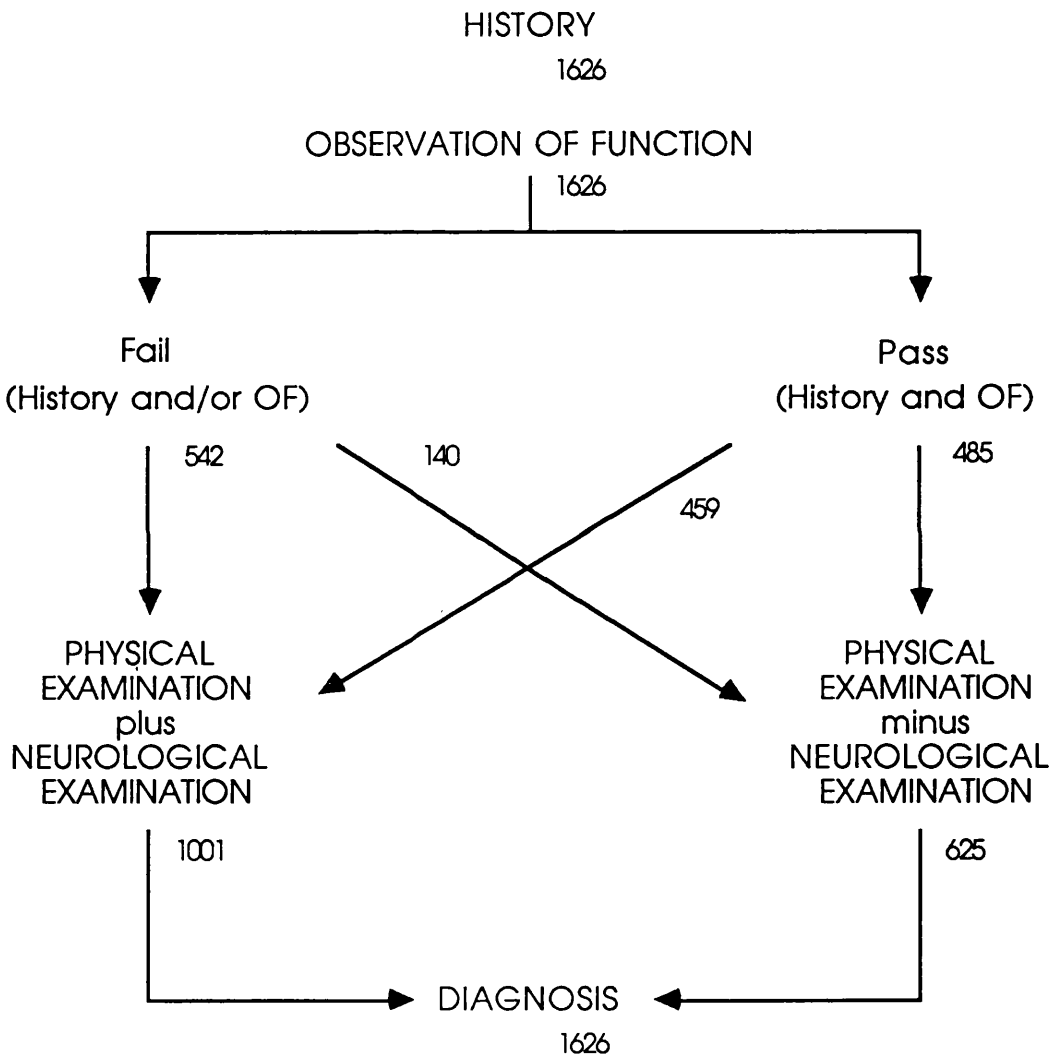


Table 4.23 : The 1626 study children categorised into four groups according to their scores on the OF and mother's history and status on the neurological examination.

Group	Fail on OF and/or mother's history	Neurological examination	Number of children
A	+	done	542
B	+	not done	140
C	-	done	459
D	-	not done	485
Total			1626

children passed the OF and the mother's history of whom 459 (Group C) received the neurological examination, and 485 (Group D) did not. The rest of this section is discussed by these group categories.

The diagnosis of 'any disability', 'serious disability', 'any motor disability' and 'serious motor disability' in the four groups is given in **table 4.24.** Maximum number of disabilities (213 'any disability', 126 'serious disability') were included in Group A, as well as most of the children with 'any motor disability' (57 out of 58) and all those with 'serious motor disability'. Group B, positive for a problem, contained the second highest gruop of disabilities (37 'any disability', 11 'serious disability'). However, there was only one child with 'any motor disability' and none with 'serious motor disability'.

Groups C and D had 12 and 22 children with 'any disability' respectively, of which only

Table 4.24 : Diagnosis of 'all disability', 'serious disability', 'all motor disability' and 'serious motor disability' by the four groups described in Table 4.23.

Groups	N	all disability	serious disability	all motor disability	serious motor disability
A	542	213	126	57	35
B	140	37	11	1	0
C	459	12	0	0	0
D	485	22	5	0	0
Total	1626	284	142	58	35

Group D had five children with 'serious disability'. None of these groups had children with motor disabilities. This demonstrates that almost all children with a potential motor problem were included in Group A.

However, this still meant that about a third of the total number of children (542 out of 1626, ie. 33%) had to be neurologically examined. This group had sub-categories according to the

combinations of scores on the OF and the mother's history. The breakdown of these sub-groups is given in **table 4.25**. Group A1 (fail in the OF and in the mother's history) contained all children with 'serious motor disability' and most children with 'any motor disability' (43 out of 58). Group A2 (fail in the mother's history and pass in the OF) contained 14 children with 'any motor disability'. Group A3 (fail in the OF and pass in the mother's history) contained none with motor problems. For the definitive diagnosis of motor

Table 4.25 : Breakdown of the 542 children in group A into three sub-groups according to their combination of scores in the OF and mother's history*, with diagnosis of 'all disability', 'serious disability', 'all motor disability' and 'serious motor disability' in each sub-group*.

Groups	N	all disability	serious disability	all motor disability	serious motor disability
A1	120	110	95	43	35
A2	409	101	30	14	0
A3	13	2	1	0	0
Total	542	213	126	57	35

* A1 = failed OF and mother's history
A2 = passed OF and failed mother's history
A3 = failed OF and passed mother's history

disabilities, the neurological examination could have been restricted to group A1 to include all serious motor disabilities or group A1 and A2 to include milder motor problems.This would have brought down the number of children to be examined neurologically considerably.

8.2.Cases and controls: age and sex distribution:

In order to compare the results on the neurological examination, Group A was considered

as 'cases' and Group C was considered as 'controls' for the neurological examination. **Table 4.26** gives the distribution of the mean age of the two groups and their sex ratios. They were comparable on these two parameters.

Table 4.26 : Age distribution and gender ratios of cases (group A) and controls (group C) in children given the neurological examination.

		Age (years)		
		Mean	± SD	Male : Female ratio
Cases:	Group A	5.80	2.29	1.35
Controls:	Group C	5.51	2.25	1.30

8.3. Comparing the positive signs in the neurological examination in cases and controls:

The neurological signs in MAF p.10 (Appendix 4) were condensed to form one dichotomous variable called 'positive NE'. All variables from m201 to m227 were considered either as 'pass' (score=1) or 'fail' (score =2,8). Another variable formed was called 'number positive', indicating how many signs were positive for each child. A total of 13 signs were computed for analysis. These were :

1. Gait=m201
2. Right and left hand dexterity=m202 and m203
3. Frogged position=m204
4. Scissoring=m205
5. Hypotonic limbs=m206, m207, m208 and m209
6. Hyertonic limbs=m210, m211, m212 and m213
7. Involuntary movements=m214
8. Instability,ataxia or titubation=m215

9. Diminished or absent reflexes=m217, m218, m219 and m220

10. Exaggerated reflexes=m221, m222, m223 and m224

11. Proximal muscle weakness=m225

12. Distal muscle weakness=m226

13. Sensory loss=m227

Table 4.24 had shown that the number of disabilities was nominal (12 mild disabilities) in the controls (Group C). To see whether this was also reflected in the neurological examination, the number of children who were positive on the neurological examination amongst the two groups was calculated for significant differences. The number of signs positive was also calculated. These are shown in **Table 4.27.**

Ninety-four out of 542 children (17%) amongst the cases were positive on one or more signs in the neurological examination compared to 14 out of 459 (3%) of the controls. A

Table 4.27 : Distribution of children with positive neurological signs (%) in cases and controls. Sub-groups of cases (group A) given in italics.

Groups	Number	Positive Neurological	(%)
Cases	**542**	**94**	**(17.34)**
A1	*120*	*52*	*(43.33)*
A2	*409*	*41*	*(10.02)*
A3	*13*	*1*	*(7.69)*
Controls	**459**	**14**	**(3.05)**

breakdown of cases into the 3 sub-groups shown in italics (subgroups described in table 4.27) showed that Group A1 had a higher number of positive (43%), the second highest being Group A2. This compared well with the outcome of the diagnosis for disability (especially motor) as

shown in table 4.25, indicating that neurological examination was more useful in the 'cases', with more positive signs, and most useful in sub-group A1 , which contained all children with serious motor disabilities and almost all children with mild motor disability.

The breakdown of the specific signs which were positive in cases and controls is given in **table 4.28.** The most frequently scored problems amongst cases were of gait, abnormal reflexes, distal and proximal muscle weakness and finger dexterity respectively. There were, however, children in all the categories of signs. Amongst controls, most categories of signs elicited normal responses, accept for abnormal reflexes and muscle weakness.

Table 4.28 : Specific neurological signs which were positive in cases and controls expressed as percentages of the total children in each group.

	Cases (n = 542)	Controls (n =459)
gait	9.2	0
finger dexterity	2.4	0
frogged position	0.4	0
scissoring	0.4	0
hypotonic limbs	0.7	0
hypertonic limbs	1.3	0
involuntary movements	0.6	0
ataxia	1.3	0
absent or diminished reflexes	5.5	2.4
exaggerated reflexes	5.9	0.9
proximal weakness	4.1	0.2
distal weakness	4.1	0.2
sensory loss	0.4	0

8.4. Conclusions on the neurological examination:

This examination was most diagnostic for disability in those children who had been either positive on the mother's history and/or failed the OF. Others who did not fall into this category had non-specific illnessess. None had neurological impairments and could have been exampted from the examination.

CHAPTER FIVE

Discussion on Part A

Introduction

To reiterate the points made in Chapter One, research involving comprehensive neurodevelopmental assessment (NDA) of childhood disabilities can be challenging to conduct in developed countries. One must confront problems of standardised ascertainment procedures, definitions, and recognition of which kinds of disabilities must be recognised for treatment and intervention. When this same research is attempted in developing countries, the problems are magnified manifold because of various manifestations of underdevelopment, lack of resources, lack of trained personnel, etc. Given the problems of a meagre health system with a very large physician-to-population ratio, illiterate mothers, an abundance of children not all of whom go to school, and logistic problems of poor communication and transportation systems, research within communities of developing countries has to be innovatively planned and implemented.

Cognisant of these special circumstances, a simple, brief and functional test was developed to identify disability within the structure of the neurodevelopmental assessment, to aid physicians in their examination and to help save time. Three assumptions were made in the planning and conduct of this study. They are:

1) that observing a child perform a set of structured functional tasks can identify disabilities, specially motor disabilities, reliably and validly,

2) that the test can be used in a decision making tree within the neurodevelopmental assessment format,

3) that the procedure can be used to exclude children from the full neurological examination.

The discussion that follows will try to answer whether the assumptions made were warranted. Salient points emerging from the study and specific lessons learned from the process will be underscored. A conclusion to this part of the study will be provided at the end of the chapter.

1. Did the OF identify disabilities, specially motor disabilities, validly and reliably?

This study showed that the overall score of the OF was able to identify almost half (44%) of all disabilities and almost three-quarters (72%) of serious disabilities. In the disability-specific sub-categories it did better for all serious grades of disability. The best scores were in the motor functions. In addition large numbers of speech and cognitive problems were also identified. Hearing and vision problems were the least identified. However, as the structure of the test had been more focussed towards picking up motor problems, it was gratifying that problems in other domains were picked up as well, and this may be regarded as a boost to the positive outcomes of the study.

There were some unique characteristics shown in the results which need further discussion and should be a caveat to the interpretation of results. These were the following: 1) multiple problems were identified more accurately than isolated problems, specially of speech, vision and hearing, 2) an age bias was shown between younger and older children; bias was also seen between study sites. None of the biases applied for serious motor disability, which was universally identified.

For the sake of clarity, each functional domain and corresponding disability and the accompanying source of bias is now discussed separately.

1.1. Motor Functions:

Every normally developing child should be able to walk by 18 months (Neligan and Prudham, 1969; Frankenburg et al, 1971), and by two years show evidence of greater maturation of gait (Gesell, 1940; Statham and Murray, 1971). Delays in motor development and/or abnormal gait patterns by themselves, thought to be the least predictive of later neurodevelopmental outcome (Illingworth,1987a), may on the other hand persist as serious problems in school (Drillien and Drummond, 1983). The advantage over other functions is that they are easily observable. This was reflected in the high sensitivity of the OF for motor

dysfunctions.

There were discrepancies in identification by age. More of the two-year-olds were identified for motor delay than in any other age group. It is the general consensus amongst developmental specialists that to identify motor abnormalities/delays in early childhood is wiser than to ignore them completely (Illingworth, 1958; Holt, 1981). Although most children go on to develop normally (Knobloch et al, 1979; Nelson and Ellenberg, 1981), some may suffer from a more chronic condition. Depending on the underlying pathology, the course of the problems could be static or progressive (Neville, 198), and need to be followed up. Whether children in developing countries are late walkers due to environmental factors and child rearing practices is an unresolved issue which needs verification. However, many of these children would benefit from early intervention, treatment or rehabilitation, such as the cases of ricketts, nutritional deprivation and poliomyelitis seen in this study. Thus, even at the risk of over-estimation, evaluation and identification seems justifiable.

Another confounding factor which may have produced age bias is that the exact ages of children is often difficult to ascertain, when no birth records exist and the local calenders are used for reference. Age misreporting in developing countries is well known (Bairagi et al, 1987). Although care was taken in the study to ascertain age as carefully as possible, it is probable that a number of those labelled as two-year-olds could might have been not yet fully two, so that they were actually within their developmental schedule, but spuriously classified as being delayed.

Conversely, in 13 older children (over five years of age), the OF missed mild motor disability. This may be attributed to the test construction. It may be argued that the test tasks were too easy for the older child. When a test becomes too easy to the child there is a loss of 'face validity' of the test (Rust and Golombok, 1989) and this must be taken into consideration. A more difficult gross motor task (such as climbing steps, running, hopping, or walking on a straight line) or fine motor task (such as threading a bead, etc.) might have revealed the more covert problems. Yet the argument looses impact when the diagnosis of these children is

considered. Most of them had isolated motor problems like talipes, Erb's palsy and mild facial palsy, which might not have discernable effects on the daily living functions of the child. The merits of treating these conditions is also questioned. It has been shown that evaluation of the surgical treatment of club foot was concentrated more on residual deformity than on useful movement of the ankle (Hutchins et al, 1985), the status of which may not change post operatively. However, three children had mild motor delay associated with speech and cognitive disability, and they might have been identified on a more elaborate/difficult motor test task.

Possibilities of modifying the tasks within the OF with more challenging tasks for older children are discussed later in this chapter.

1.2. Speech functions:

Next to motor functions, the most common problem the OF identified was speech functions. The criterion for failing the child for speech was based on a few questions asked of the child together with the observation made during the history taking. These seemed to be adequate for accurate scoring. As we know, there can be great variations in speech development depending on a range of factors, environmental and constitutional (Illingworth, 1987a; Gesell et al, 1939). The development and quality of a child's speech has the highest correlation of all aspects of behaviour with the child's later intelligence (Capute and Accardo, 1978), and early development of speech almost certainly excludes mental retardation. Longitudinal studies of school-going children in developed countries have shown that although most children outgrow their speech delays, a significant number go on to have learning and behavioural problems in later life (Stevenson and Richman, 1978; Drillien and Drummond, 1983). Speech disorders might also be an outward expression of an underlying hearing or cognitive problem which requires thorough assessment (Illingworth, 1987c).

Given the number of problems that speech patterns herald, it was encouraging to see that most were identified by the OF, specially in the serious categories. This was an unexpected

result, as even in the best of circumstances it is difficult to get children to talk and get samples of language within assessment settings (Reynell, 1969), and there are cultures which discourage children from 'talking to strangers' (McConachie, Personal Communication). The natural setting of the study within the child's own community may have helped him/her to overcome any such inhibition. Whether the same procedure can be transferred to clinic settings needs to be ascertained.

Of all children with multiple problems associated with speech disabilities, 87% were identified. These are the children who are at greatest risk of a persisting problems in later life, and could benefit most from intervention programs. By comparison only 37% of those with isolated speech problems were identified. However, longitudinal studies have shown that the latter are the children who develop normal speech eventually, much of the delay being attributed to environmental deprivation or familial delay (Drillien and Drummond, 1983; Davie et al, 1972). Five of the eight children with serious speech disability that the OF missed had multiple problems, including three with mild mental retardation and five with hearing disability. All were older children. In these cases a more stringent threshold for diagnosing speech problems, eliciting speech patterns compatible with their chronological ages, could have revealed their disability.

A spurious type of bias in assessing both speech and language functions might have occurred in site 5 (Chittagong) of the survey. This is because this particular district of Bangladesh speaks a dialect which is very difficult for the examiner to understand. Appendix 5 and Appendix 6 show the unusually large numbers of children that were diagnosed as having an isolated speech disability (ie. more than half of all children with speech disability) even in the serious grades. One wonders who was the disabled - the examiner or the child! It has been argued that ethnic differences causing faulty communication between the two may lead to such spurious diagnosis especially of language and communication disorders in the child (Bernard Coard, 1971). Even within the same country different dialects exist and cultures vary, and was a very likely source of bias in this instance.

1.3. Language and comprehension functions:

Both these functions on the OF were compared with cognitive disabilities in the diagnosis . The OF did not do as well in identifying cognitive disability of all grades of severity (24%) as it did for serious problems (76%). The difficulties inherent in assessing cognition are well recognised especially in the context of varying cultures (Serpell, 1988; Scarr, 1981). Studies such as the one reported by Tomlinsen (ref) showed the over-identification of children of West Indian origin as ESNs. Therefore any result must be judged with these difficulties of ascertainment in mind.

As mentioned above, both the language and comprehension functions were considered together. The reasons for this is that they are functions which are interrelated and have close correlations to each other in terms of the child's future (Bishop,). The subjective impression of the examiner was that comprehension was judged more on the basis of the response of the child to the more Piagetian tasks such as reaching for the object and giving it to a stranger/mother, etc. while language functions were judged on the basis of responses (both verbal and non-verbal) to verbal requests and questions.

It could be that requests such as 'give these to Mummy' (meaning the bead and the coin), 'show me the coin', 'what did you pick up?' 'what colour is this bead?', etc. revealed language and comprehension deficit. Again, the subjective feeling of the examiners was that there were certain behaviour patterns noted during history taking and testing on OF that gave important clues to the cognitive functioning of the child. The best clues seemed to the alertness, interest and social demeanour shown by the child to the uniqueness of the circumstances (ie. strangers in their village who carried all kinds of interesting gadgets and toys); responsiveness; interaction with the mother and peers (children were everywhere during the assessment) and not least, the extra undefinable 'glint in the eyes'. None of these factors, termed by Gesell as 'insurance factors', have norms attached to them, but they have been acknowledged by developmental specialists as invaluable in assessing mental development (Illingworth, 1987; Hall, 1989). On record, in the directions preceding the OF, instruction 2 explicitly stated that

such factors as social smile, shyness, responsiveness and any form of vocalisation must be taken into account when scoring. These 'insurance factors' seemed to have helped in scoring for language and comprehension functions.

In the Infant Behaviour Record of the Bayley Scales of Infant Develoment, similar patterns of cooperativeness, attention span, etc. are recorded and have been shown to be the good predictors of later outcome (Bayley, 1969). They could be applied to older children, as has been incorporated in the Reynell scales of language development (Reynell, 1969).

The majority of the 42 children that the OF failed to diagnose fall into the category of isolated mild mental retardation (MMR). Eleven children with serious mental retardation (SMR) were missed, of whom eight had isolated problems of cognition. Data from developing countries reveal that SMR children are comparable with similar children in western countries in having associated impairments, parental consanguinity, more worries in their parents about ther functioning, etc. (Stein et al, 1986). It is argued that the ones with isolated SMR, in better circumstances, would have been categorised as MMR in developed countries. Problems of case definition, IQ testing using norm-referenced psychometric testing, etc. also compound the issue (Alberman, 1984), so that had the children been school-going or been taught pre-school skills, they might have performed better on psychological tests used (Serpell and Nabuzoka, 1991). It is interesting to note that all the eight children were older, between seven and nine years old. Again one wonders if the OF was too easy for their chronological age and whether more a difficult cognitive task, such as some form of verbal reasoning like 'what would you buy in the shop with one taka?', could have given better clues and been more helpful.

1.4. Hearing functions:

The OF did poorly in identifying disabilities of hearing. Only a quarter of all disabilities and over half of serious disabilities were recognised. This result was not unexpected as the OF had not been designed to pick up hearing problems per se. All except one child of the 18 children who were identified for any hearing disability had associated impairments and disabilities of

speech, language, motor problems and cognition, in various combinations; their functional impairment could be attributed to multiple problems which were easier to identify. Whether impairment of hearing functions was the cause or effect was more difficult to ascertain.

The frequency of developmental disability is more common amongst the hearing impaired (Schein and Delk, 1974), and conversely hearing impairment is more common among developmentally delayed than normal children (Conley, 1973; Vernon, 1970). Hence a failure in any of the functional domains (especially hearing, speech, language and comprehension) would be an important indicator for formal hearing tests. Many of underlying pathology such as chronic suppurative otitis media are treatable at very low costs. Alternative communication could be estabilished early for those children with perceptive deafness. These available benefits of early identification strongly support its value as an study objective.

It is generally more difficult to identify isolated hearing loss. Partial sensori-neural hearing loss is more common than total deafness and is even more difficult to detect (Coplan, 1987). Of the 11 children with serious hearing loss that the OF failed to identify, more than half (six) had perceptive deafness. Development of these children is usually quite good in the other domains, almost as a compensatory phenomenon to the deficiency in hearing. For example, they seem extremely good at taking visual clues. It is plausible that the verbal request of the examiner to the child to carry out the task in the OF could have been betrayed by such clues inadvertantly.

Only two out of the 18 children identified were two-year-olds. This points to the difficulty of identifying hearing loss in younger children and differentiating functional speech from language delays (Rutter and Martin, 1972).

The background noise level in the examination area might have been another deterrent in identifying children with mild to moderate hearing loss (40db to 60db) as the examiner might have had to raise the voice louder than the required conversational level, thus missing milder problems. It also raises the issue of what is functional loss of hearing and how much it corresponds to the absolute criteria in decibels that were used for diagnosis. The WHO criterion of 'listening behaviour' seems a more practical guideline to follow (WHO, 1980).

Formal tests of hearing cannot be compensated by the OF, unless more refined functions are incorporated with it, such as making the verbal request from behind the child, conceptually resembling the performance and co-operative tests.

1.5. Visual functions:

Visual functions were identified in the least number of children. Of the 11 identified (out of a total of 51 visually disabled chidlren), four had isolated vision loss. Two of these children had obvious signs of Vitamin A deficiency leading to near-blindness and one had a squint. Out of the 12 children with serious vision disability that the OF failed to identify, all but one had isolated vision disability diagnosed on the basis of the result on the vision charts for visual acuity. The functional correlates of these results may be questioned, and this is one criticism of the diagnostic criteria for vision set up by the study. More aspects of visual behaviour, such as visual alertness, tracking and rapidity with which an object is focussed upon, would tell more about the child's vision (Sonksen, 1983).

Studies have shown that children with visual handicaps recognise and pick up objects quite functionally, even though they might be seeing only the vague outlines of the objects (Slater, 1990). Such strategies are even more developed in children with isolated vision problems, who have been known to develop extraordinary skills through the faculties which are intact.

To make the OF more sensitive to vision problems, functional tests of vision would have to use much smaller objects (the size of hundreds and thousands) to obtain better results.

1.6.Reliability of the OF :

Test retest agreememt was better than the interobserver agreement. In the former, the function-specific agreements were excellent while agreement on the overall score of the OF was substantial. The 68 children re-examined belonged to two sub-sites in site 2, and included all children from those sites who required a professional evaluation. This reduced the children with fucntion specific problems to only a few. A larger sample with more problems is required to

confirm this result.

In the interobserver agreement, the motor function-specific agreement was substantial. Agreement on the overall score was only fair. This points to the fact that perhaps there is a discrepancy in what is being measured and scored by each physician that needs to be clarified. Training based on more structured and clearly delineated criterions improved the agreement between examiners for diagnosis of cerebral palsy (Blair and Stanley, 1985); and excellent agreement seemed to exist between neurologists to interpret neurological signs in their adult patients (Sisk et al, 1970). More intensive training and better agreement between examiners therefore must be instituted before using new procedures. In the case of the OF, the two examiners might have interpreted the same function in separate ways: one examiner scoring fail on individual functions (eg. failing a child who had a limp), another examiner scoring only the child if he/she was functionally distressed (eg. not able to walk with the same ease and speed of another child the same age).

2. Can the OF be used in a decision-making tree within the neurodevelopmental assessment?

As stated in Chapter One, objectives of the neurodevelopmental assessment may vary at different times. Emphasis on the selection or formulation of an assessment procedure vis-a-vis the purpose of the assessment and subsequent decisions to be made reflects a perspective known as decision theory (Cronbach and Gleser, 1965). Accuracy and yield of the test is only valid insofar as it facilitates a qualitative decision about the child. The value of the OF in making such decisions within the sequential events of the neurodevelopmental assessment has been demonstrated in this study.

An outstanding aid to neurodevelopmental assessments is an accurate account about parental concerns and worries about their child (Glascoe et al, 1989). In developed countries that parents are concerned about their child's development has been demonstrated repeatedly (Hickson et al, 1983), parents from underprivileged social groups being no less worried (Davie

et al, 1972). Although a substantial body of literature exists regarding the plight of the family with a disabled child in developing countries (O'Toole, 1989), none tells us about the perception of the mother regarding the development of her child, compared to a comprehensive neurodevelopmental and psychological assessment.

This was demonstrated well in this study. Mothers, irrespective of socioeconomic status, literacy, or being urban or rural, unequivocally identified developmental problems in their children, a finding supported by similar findings in developed countries (Johnson et al,1986; Knobloch et al,1979). That the sensitivities and specificities in the function specific concerns were high reflects that their answers were not just a 'leap in the dark'. In developing countries where there is no access to health services, any enquiry about the child might result in a positive response, in the hope that some benefit could be derived from the system.

It may be said that this notion was disproved in the study.

The high levels of sensitivity and specificity according to which the mothers identified problems in their children is comparable with their response on the TQP to the community worker (Zaman et al, 1990). Differentially, some developmental problems such as motor and speech were more frequently reported than hearing, vision and comprehension. Overt problems of ambulation could be a serious handicap to children in communities where walking is the only means of mobility, compared to the more 'hidden' impairments such as mental retardation (Fryers, 1981). The differential attitudes and difficulties of families to different kinds of disability and handicap in a child needs to be ascertained before intervention is planned, as this will strongly affect motivation and long-term compliance.

Within the decision-making process, the OF was used after the history taking, to reach a decision about whether the child required a detailed neurological examination or not. The yield of combining these two procedures sequentially was considerable in terms of the number of children that could be eliminated from the neurological examination. It was also considerable in terms of the time that could be saved, so that more time could be spent assessing those found to be have functional problems which required accurate diagnosis where possible.

Thus, when combined with the mothers history, the OF may function as an important aid in the decision-making process within the neurodevelopmental assessment when large numbers of children have to be seen.

3. Could the OF identify those children who did not require the neurological examination?

The analysis of cases and controls for the neurological examination revealed that no child with a significant disability, especially neuromotor disability, was missed by the combined assessment on the mothers history and the OF. Minor neurological dysfunction that help to diagnose clumsy children, children with mild cerebral palsy, movement disorders, and mild neuropathies are difficult to ascertain even in ideal situations (Touwen, 1979). In addition, their presence or absence does not necessarily imply presence or absence of underlying problems. For practical purposes identification of these children was not within the remit of this study, which was focussed upon diagnosis of functional disabilities relative to the unique situation and circumstances of the child.

There were no cases of motor disability diagnosed amongst the controls, although 21 other forms of disability, including five serious disabilities occurred in this group.

Amongst cases, the neurological examination aided the physician in coming to a definite diagnosis regarding the underlying cause of the child's disability. The signs most commonly used, and which were often positive were the reflexes, muscle tone, and muscle power. They helped primarily in discriminating upper and lower motor neurone lesions; in categorising cerebral palsy according to type and site; and in diagnosing non-specific delay in those motor impaired children who had no positive neurological signs. The only positive neurological signs amongst controls was muscle weakness, diminished reflexes accompanied by normal muscle tone, which are common signs of systemic illness or fatigue (Baird and Gordon, 1983, page 78).

There were important adjuncts to the neurological testing that was omitted from the study

and which could have aided in the more precise diagnosis of cerebral palsy, etc. More time per child could have also aided this.It is however arguable how precise and diagnostic can a single evaluation within community settings be within such limited time and resources.

4.Conclusions:

It can be said with conviction that the three assumptions made at the beginning of the study were justified. The OF has proven to be a valid and reliable procedure for the rapid identification of serious disabilities in children, with particular emphasis on motor disabilities. To help the OF to function within a sequential decision-making process within the neurodevelopmental assessment, the accuracy of the mothers' concerns about her child's problem has been invaluable. In fact, it has been shown that the OF can only operate as an adjunct to the mother's history, as it does no better than the mother in identifying problems, and in some cases performs worse. (This notion is carried over to the next chapter which tests the value of the OF when done by CWs in the child's home, and as an adjunct to the TQP). The OF also reduces considerably the numbers of children who need a more thorough evaluation of neurological signs. There seems to be ample scope within the OF for modifications to increase its sensitivity for vision and hearing problems. There is also scope for putting in some functions that are harder and more challenging to older children, a category in which the capacity of the OF seems to be stretched.

Implications for modifications, and possibilities for future application of the study are discussed in Chapter Seven.

CHAPTER SIX

THE USEFULNESS OF THE 'OBSERVATION OF FUNCTION' WHEN USED BY COMMUNITY WORKERS IN IDENTIFYING CHILDHOOD DISABILITIES

Introduction

The newly obtained independence of many countries in the post-war period saw a growing emphasis on the concept of equitable distribution of health services and primary health care (PHC) among the remote rural populations and to the underprivileged (Banerji, 1974; Navarro, 1974; Bryant, 1977). This led to the gradual shift from the medical model of health to the social model, which was integrated with other aspects of life such as sanitation, food, financial solvency, family planning, women's development, and literacy (King, 1966; WHO, 1973; Djuvanovic and Mach, 1975). A major outcome was that health services started training intermediate health care personnel or community workers (CWs) to breach the vital gap between the people and the health delivery services (WHO, 1979; Werner, 1986).

So far the results of such programmes have been mixed. In some democracies, such as Tanzania, where the political commitment of the government was strong, the emphasis on PHC has been 'more rhetorical than real' as the true picture was a development of city-based, treatment-orientated services (Heggenhougen et al, 1987). One of the key factors for the failure of PHC was that CWs, with minimum basic training, were sent out into the field without adequate backup either from the community which they served or from the medical services (Walt, 1990). There were also some successes: in China the 'barefoot doctor' became the mainstay for dissemination of health care to the people on an unprecedented scale (Rohde, 1989). The success of their work was only possible because of the holistic approach that was taken, combining community participation, political will, endogenous traditional medicine, women's development and reliable back-up from hospital-based medicine, thus making the barefoot doctor's work realistic, accountable, and gratifying (Chen, 1989).

On the other hand, there were countries like Cuba which attained successful and equitable health care systems based on a medical and centre-based model which was heavily doctor dependent (Werner, 1989). Thus whilst universal PHC has been a common goal, each country has tried to mould it to its own unique culture, socio-economic infrastructure, resources, topography and people.

The need to reach out to every disabled person in the community is by comparison a newer concept which came into focus chiefly in the late Seventies and early Eighties after substantial successes had been attained in the control of morbidity and mortality of more acute problems (WHO, 1982). WHO provided the impetus with the publication of a manual (Helander, Mendis, and Nelson, 1983), the goal of which was to demystify the rehabilitation process and give responsibility back to the individual, family and community. In the past decade, 'Community based rehabilitation' (CBR) has become an oft-repeated term, often inviting criticism as a panacea for divergent cultures (Miles, 1986) and the justification of which was based on *a priori* rather than empirical grounds (Wedell and Roberts, 1982; O'Toole, 1990).

In fact, the issues affecting CBR are not too dissimilar to those that have helped in the failure or success of PHC. No matter what the rhetoric and the policy on paper say, most 'CBR workers' are utilised in centre-based treatment and therapy programmes, similar to the more developed countries. Not unexpectedly, these programmes have remained city or town based and have benefited only a few. Conversely, the practical feasibility of the newer approach in identifying disability at home and involving parents, siblings, or any other person in the community in helping the disabled person to become more functional, has been questioned (Jaffer and Jaffer, 1990). A criticism of this approach has been that too much responsibility for the disabled child is thrust on the family, especially the already overworked mother, without any adequate backup.

The WHO has adopted a middle-of-the-road policy. The manuals that have been created for the different types of disabling conditions are meant to be used by CWs either in the child's home or in centres. A critique of this approach is that the CBR worker is expected to screen,

evaluate and rehabilitate the child. The question of whether this puts too much responsibility on the CW has also been raised.

Where no formal records about the children exist, the entire responsibility for screening, evaluating and rehabilitating disabled children (cf. Section 4, Chapter 1) within the community is a formidable task, especially when some of these children need a thorough evaluation of neurodevelopmental problems, many of which need to be diagnosed and treated (eg. in cases such as TB spine)[1]. The DDST-type of norm-based evaluation being standardised in several developing countries by WHO for use by CWs, is again subject to criticism, as it involves a long process that needs to be laboriously standardised in each country, stratified by geographic locations (urban versus rural), gender, etc. More realistic and valid methods of evaluation are required.

The key concept behind the REA study (cf. Chapter 2) was to find methods of effectively utilising CWs in epidemiological studies of childhood disability, backed up by a team of doctors and psychologists to perform definitive evaluations. The services of the CW were utilised for screening purposes, and those of the professionals for evaluation, treatment and planning for rehabilitation. Given the lack of trained resource people, and expectations that the CWs would eventually be the mainstay of rehabilitation, their involvement in more evaluatory processes was seen as a step forwards in bridging the gap between the community and sophisticated services. After screening for disabilities in a child, if they (CWs) could also carry out some preliminary evaluation effectively, it would be cost-effective, insofar as decisions could be made by them about which children required more thorough and sophisticated investigation. This was further justified by the fact that many of the screened population were expected to have impairments which could be treated by simple and tested means by CWs (cf. Section 1, Chapter 4).

---

[1]Instances have occurred where a child with post polio paresis of the lower limb has been given intense physical therapy for a whole year without substantial effect when more benefit could have been obtained by an ambulatory aid (personal report, unpublished)

The impetus for this part of the study evolved when initial analysis of the 'Observation of Function' (OF) showed that it was effective in identifying serious motor disabilities and a high percentage of serious hearing, speech and cognitive problems. These results combined with its brief and noninvasive characteristics, led to the notion of verifying its use by CWs in the screening stages, to see whether they could carry out the same procedure as the physicians. This would be backed up by the evaluation by physicians, and provide future directions to the kinds of simple evaluations that could be developed. Such functional evaluations, if valid and reliable, could be an adjunct to the screening in epidemiologic studies, or part of more definitive assessments before and during conduction of CBR work using matarials like the WHO manuals.

This chapter presents the events in Bangladesh that led to this study (background), the methods and materials used, results, discussion and conclusions derived from the study.

1.Background and aims of the study.

Soon after the completion of the field work for the REA study (July 1988), Bangladesh suffered the worst floods in fifty years, when three-fifths of its habitable land went under water. The REA team decided to re-evaluate the children in site two (Dhamrai), which was one of the worst affected areas.

The principal aims were to determine the extent to which, in the face of a natural disaster, disabled children were at increased risk compared to other children for mortality, illness and psychological distress; and to determine the extent to which families with disabled children experienced displacement, property loss, morbidity and mortality than families without disabled children.

A secondary aim was to test the reliability and validity of the 'Observation of Function' (OF) when administered by CWs. This part comprised Part B of this thesis and will be elaborated here.

The two-stage screening-evaluation study design of the REA study was retained. All

children who had been eligible for professional evaluation (TQP positive cases as well as TQP negative controls) in the REA study, were readministered the TQP in their households. Two weeks later, all the 70 children identified as disabled in the REA study were re-evaluated by a team of paediatricians and psychologists at a central location in each particular village. For every disabled child seen, two non-disabled children, matched for age and sex, were seen as controls.

2.Methods

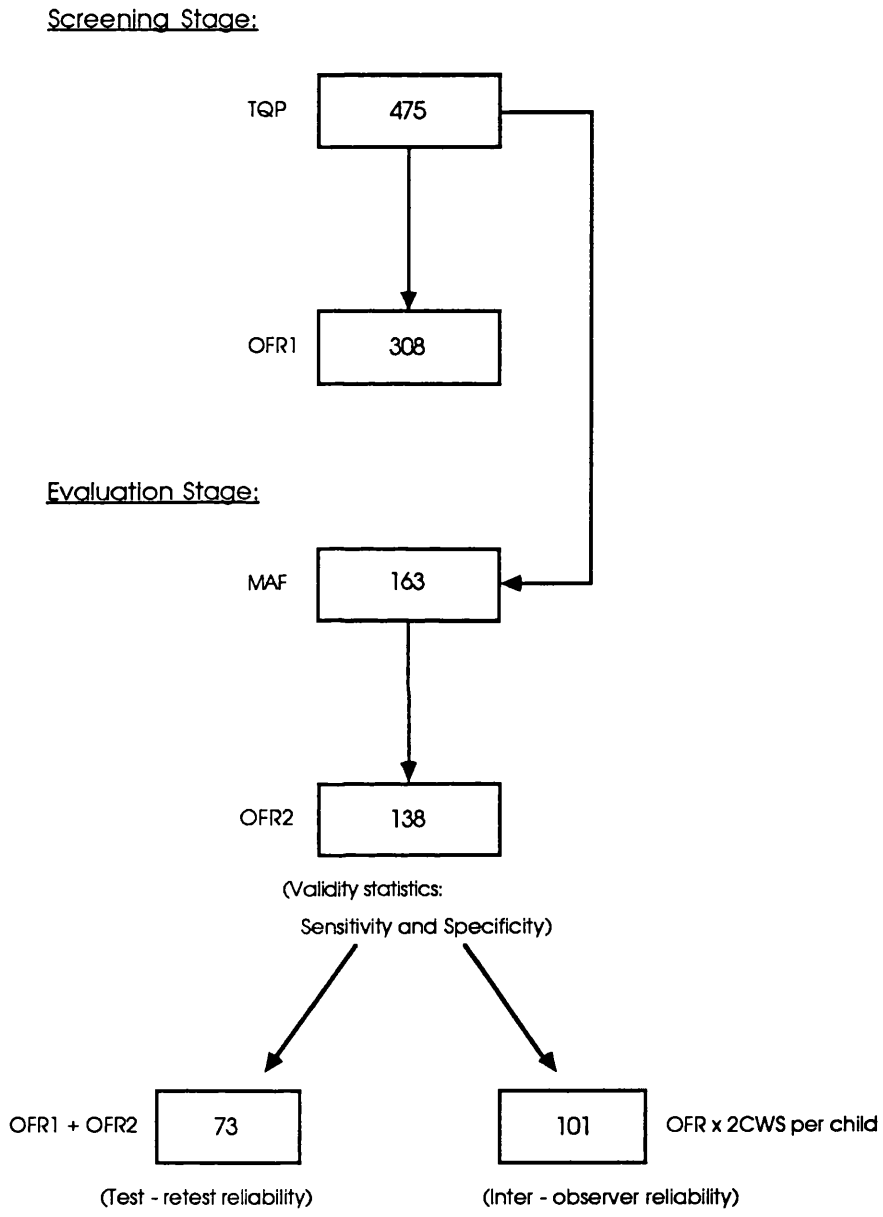
2.1. The Study Instrument:

The OF was translated into Bangla, the wording was simplified, and it was renamed the 'Observation of Function Revised' (OFR). The full retranslated version in given in **Appendix 8.** The CWs were trained to use it in two one-day sessions by N.K. on disabled and non-disabled children. The concepts underlying delayed or impaired development of walking, using hands, visual behaviour, speech, language and comprehension was discussed. The functions that are observable when a child walks, squats or stoops, picks up a coin and a bead, gets up, answers questions and draws a shape, were elaborated. The training was not made too lengthy, as one of the intentions within the study was to get a true picture of the CWs' perceptions about functional disability, without the burden of too much new theoretical information.

2.2. The Study Design:

In the first or screening stage, the OFR (OFR1) was administered to each child in his/her homestead, after completion of the TQP (**Fig. 6.1.**). Approximately two weeks later at a central location within the particular village, the children who had been identified as cases and controls from the REA study (see previous section: Background), were assessed by paediatricians and psychologists. At this time the children were readministered the OFR (OFR2)

Fig. 6.1 : Study design showing the number of children seen at each stage, and the types of analysis done (in parentheses), by groups .



by CWs (**Fig.6.2**). For some children it was done for the first time as they had not been found at home during the home-visit. For each child, the CW who had completed the OFR1 did it again on the same child during the assessment. One other CW simoultaneously scored the child too. They were also given responsibility for screening audiometry and anthropometric measurements.

The numbers of children seen in the screening and evaluative stages of the study is given in Fig. 6.1. In the screening stage 475 children were administered the screening questionnaire (TQP). Of these, 308 children were administered the OFR1. In the second stage, 163 children were professionally evaluated. Although all of them had the OFR2 administered at the time, 138 fully computed records were used for analysis due to missing data. Of these 138 children, 101 children had their OFR2 scored simultaneously by another CW. For 73 children it was

Fig. 6.2. : Community workers using the OFR.

administered by the same CW who had completed it in the child's home.

2.3. The Study Population:

The gender distribution of the 138 children who were both professionally evaluated and had completed OFRs (OFR1 and OFR2) was 70 (50.7%) boys and 68 (49.3%) girls. There were only two two-year-olds, and three seven-year-olds. 68 children (49%) were aged eight years or older. One boy was twelve years old.

Table 6.1 : Neurodevelopmental disorders diagnosed in the 138 study children used in the validity study. Figures in parentheses are the children with serious disabilities.

	all	serious
mental retardation with impaired hearing	10*	(1)
conductive hearing loss	11	
xeropthalmia with/without conductive hearing loss	8	
post-polio paresis	5	(3)
speech delay with mild mental retardation	4	(1)
cerebral palsy with associated problems	2	(1)
delayed speech only	2	
poor visual acuity	2	
global delay	1	(1)
epilepsy	1	(1)
TOTAL	46	(8)

* 3 = perceptive deafness
7 = conductive loss

The kinds of neurodevelopmental disabilities (NDD) found in the 138 children is shown in **Table 6.1.** There were a total of 46 children with disabilities of all severities. Hearing disability with or without associated problems was the single most common diagnosis made (in 27 children), probably enhanced by an increase in otitis media due to children living and playing in water during the floods. Mild mental retardation (MMR) associated with problems of vision and hearing, usually of an infectious/nutritional nature, was diagnosed in 14 children.

Seven children had serious disability, of whom two had post polio paresis, one had epilepsy not associated with other problems, one had MR with hearing problems, one had MR with speech problems, one had global delay, and one had cerebral palsy. Speech functions was scored in the serious category in the two children who had global delay and MR respectively. In the child with cerebral palsy, his cognitive functions were scored as serious, the motor disability being of a milder nature.

2.4. The Community Workers:

There were five CWs in all. These included four females and one male. All of them had graduated from secondary school (class 10). All, except one female CW, had been part of the REA study. They therefore had a very good idea of the kinds of children this study was looking at, the computed forms that were required to be filled, and the meticulousness of the job (incomplete forms were not accepted and the concerned CW had to readminister it during the professional evaluation). In the meanwhile, all of them were working with physically and mentally disabled children in two centres within Dhamrai Upazilla. The WHO manual for the physically disabled was one of the tools with which they were familiar. All of them had received two weeks' training in Dhaka city in the care and management of multiply disabled children (re: toiletting, feeding, ambulation, play activities, etc.).

2.5. The Data Analysis:

The validity of the OFR was analysed in terms of its sensitivity and specificity to identify

disability; any and serious. Dichotomous scores derived from the seven function-specific questions on the OFR (OFR30 to OFR36) were made, ie. 'fail', 'uncertain' and 'no response' were amalgamated into a single score of 'fail'. The dichotomous scores were crosstabulated with the diagnosis of disability in the Summary Sheet of the MAF.

The test-retest reliability of the OFR was calculated between the 73 children . The intra-observer reliability was calculated in 101 children. The kappa statistics (k) was used to express the agreement that occurred beyond chance.

3.Results

3.1. Sensitivity and Specificity of the OFR:

Baseline information:

Dichotomous variables were derived from seven scores on the OFR (OFR30 to OFR36), ie. questions on the functions of the child in the seven developmental domains, and a final question on whether the CW thought there was any problem with the child (OFR37). A new dichotomous variable comprising all children who had failed at least one of the seven functional domains, irrespective of the response of the CW to the last question, was formed. It was named 'positive OFR' (pOFR).

The 'gold standard' with which the OFR scores were compared were the disability ratings by the paediatricians on the MAF. To give an idea of the kinds and numbers of disabilities the OFR was supposed to identify, the actual distribution of the different types of disability in the 138 children is given in **Table 6.2.** Serious disabilities are in parentheses. A total of 67 types of disabilities were found in 46 children. Twenty-three had hearing disability; 19 had cognitive disability; seven had motor disability; seven had speech disability; five had vision problems and one had epilepsy.

Eight seriously disabled children had nine serious grades of disability with or without associated milder problems. There were three motor, one hearing, two speech, and two

Table 6.2 : Distribution of the individual disabilities in the 46 children diagnosed for NDD, by age group. Serious disabilities are in parentheses. (n = 138)

Age	Motor	Hearing	Vision	Speech	Cognition	Epilepsy	Total
2	-	1	-	-	-	-	1
3	-	1	-	-	-	-	1
4	2	2	-	2 (1)	2	-	8 (1)
5	2 (2)	2	-	-	2	-	6 (2)
6	-	2	-	3 (1)	3	-	8 (1)
7	1 (1)	1	2	-	7	-	11 (1)
8	-	10 (1)	1	1	5 (1)	1 (1)	18 (3)
9	1	1	2	-	2	-	6
10	1	3	-	1	3 (1)	-	8 (1)
11	-	-	-	-	-	-	0
Total:	7 (3)	23 (1)	5	7 (2)	24 (2)	1 (1)	67[a] (9)[b]

[a] 67 disabilities in 46 children
[b] 9 serious disabilities in 8 children

cognitive disabilities. One child had serious epilepsy. This child was excluded from the analysis of the validity of the OFR, as this was not an observable functional impairment and the child did not have associated problems. None of the seriously disabled children had serious vision problems.

The distribution of the actual scores on the OFR are given in **Table 6.3.** It gives by age groups all children who scored 'fail' in any of the seven functional domains (OFR30 to OFR36), the final assessment of the CW (OFR37) and the new variable (pOFR). There were 22 positive scores in a total of 14 children. It was interesting to note the score distributions. There were no fails in the two- or three-year-olds. There were also no fails in the vision, speech, language, and comprehension domains. Three children failed in 'walking', three in 'using hands', and six in 'hearing'. The CW's final assessment as to whether the child had a

Table 6.3 : Distribution of children who failed in the seven functional domains of the OFR (OFR30 to OFR36), the final assessment by the CW (OFR37), and the new variable (pOFR) comprising any child who failed in any one of the seven domains (n = 138), by age groups.

	OFR30	OFR31	OFR32	OFR33	OFR34	OFR35	OFR36	OFR37	pOFR
Age	walking	using hands	hearing	vision	speech	language	compr.	any problem	any pos.
2	-	-	-	-	-	-	-	-	-
3	-	-	-	-	-	-	-	-	-
4	1	1	-	-	-	-	-	-	2
5	1	-	-	-	-	-	-	-	1
6	-	1	1	-	-	-	-	1	1
7	1	1	-	-	-	-	-	1	2
8	-	2	-	-	-	-	-	-	2
9	-	1	2	-	-	-	-	1	3
10	-	-	3	-	-	-	-	4	3
11	-	-	-	-	-	-	-	-	-
[a]Total:	3	6	6	0	0	0	0	7	14

[a]Only represents the column totals.

significant problem of not (OFR37) was positive in seven cases only.

Results:

Table 6.4. gives the results of the sensitivity and specificity of the pOFR to diagnose motor disability (any and serious), hearing disability (any and serious), cognitive (any and

Table 6.4 : Sensitivity and specificity of the pOFR to identify disabilities of the 'all' and 'serious' types (n = 138)

Type of Disability	n	Se	95% CI	n	Sp	95% CI
all motor	7	.42	.34 - .50	131	.92	.88 - .96
serious motor	3	.67	.60 - .74	135	.91	.86 - .96
all hearing	23	.21	.14 - .28	115	.91	.86 - .96
serious hearing	1	1.00	.90 - 1.0	137	.91	.86 - .96
all cognitive disability	19	.21	.15 - .27	119	.92	.87 - .97
serious cogn. disability	2	.50	.42 - .58	136	.90	.85 - .95
all disability	**45**	**.15**	**.10 - .20**	**93**	**.92**	**.88 - .96**
serious disability	**7**	**.42**	**.34 - .50**	**131**	**.92**	**.88 - .96**

serious), and disability in general (any and serious). Vision and speech disabilities are not mentioned as none were identified by the pOFR.

The sensitivity of the pOFR to identify any disability was 15%, seven out of 45 children being identified accurately. Of those, three had motor disabilities and four had hearing disabilities associated with mild to moderate mental retardation and/or speech problems. Ages of the seven children ranged from four to ten years. The seven others who failed the pOFR but did not have any disability seemed to be children who were at risk of having a disability. Five had been positive on the TQP, out of whom four had a recorded complaint on the mother's history in the MAF for hearing (three), vision (one), and other (two) problems. The ages of

these seven children also ranged from four to ten years. The specificity of the pOFR for any disability was 92%, with a 95% C.I. of 88% to 96%.

The sensitivity was 42% for serious disability. Three out of seven disabled were identified. This included two children with serious motor disability due to post polio paresis. The third seriously disabled case was an eight-year-old boy with moderate mental retardation, hearing problems and speech problems who had a history of birth asphyxia. Out of the four seriously disabled children whom the pOFR failed to identify, one had post polio paresis (five-year-old girl), one had moderate MR with mild hemiplegia and speech problems (ten-year-old boy), one had severe speech problems with associated mild MR (six-year-old girl) and one had global developmental delay with serious speech disability (four-year-old girl). Specificity of the pOFR for serious disability was 92%.

The sensitivity for any motor disability was the same (42%), ie. three out the seven children with motor problems of all grades of severity were identified. The pOFR failed to identify two children with mild cerebral palsy with serious MR, and two children with post polio paresis. Their ages ranged from four to nine years. The specificity of the pOFR for any motor disability was 92%.

For serious motor disability the sensitivity was 67%, 95% C.I. ranging from 60% to 74%. Out of the three seriously motor disabled children, all of whom had post polio paresis, two were identified. The specificity for serious motor disability was 91%.

The sensitivity of the pOFR for any hearing disability was 21%, with 95% C.I. ranging between 14% and 28%. Four out of 19 children with hearing disability were identified. An interesting feature was that all of them had some degree of MR as well as other associated problems of speech, language or vision. The deafness in three cases was perceptive and in one case conductive in nature. The latter was in a child who also had mild MR. Specificity for any hearing disability was 91%.

The only child who had serious hearing disability was identified accurately by the pOFR. He was an eight-year-old boy with perceptive deafness, speech problems, and moderate MR.

Thus the sensitivity was 100%. The specificity for serious hearing disability was 91%.

The sensitivity for any cognitive disability was 21%. Four out of 19 children were identified out of whom one had serious disability. All four had associated hearing problems. Specificity was 92%.

The sensitivity for serious cognitive disability was 50%. One out of every two seriously MR children was identified. As mentioned above, the child had associated hearing problems. Specificity for serious cognitive disability was 90%.

Conclusions of the results of the sensitivity and specificity of the OFR:

1. The overall sensitivity of the OFR was poor.

2. Those accurately identified had either motor, hearing or cognitive disability.

3. Of the motor disabilities, obvious and gross ambulatory problems were identified, ie. post polio paresis.

4. Of the hearing disabilities identified, all had associated problems of vision, speech, language or comprehension. No isolated hearing problems were identified.

5. The serious disabilities that were missed were children with serious speech and/or comprehension problems.

6. Vision, speech, language and comprehension domains per se were not scored at all. However, four children with cognitive problems were identified on their hearing functions.

7. Specificity scores were good, but were lessened in significance for practical purposes as many false negatives were included in those identified as normal.

3.2. The reliability of the OFR:

The results of the test-retest and inter-observer reliability are presented in this section. In both tests the pOFR scores of the first examination or examiner was compared with those of the second test or second examiner.

The test-retest reliability:

Background information: 73 children were scored by the same CW, once at home (OFR1) and once during the professional evaluation (OFR2). The sex distribution of the children was 49.3% boys and 50.7% girls. 85% of the children were aged between five and ten years. The number of children that each CW assessed was:

CW1= 6, CW2= 25, CW3= 16, CW4= 16, CW5= 10

Out of the 73 children, 18 had disabilities of any severity on the MAF. Five had serious disability. One child had serious epilepsy which was excluded from the analysis.

On both the OFR1 and OFR2 there were no 'fails' in the vision, speech, language, and comprehension domains. One can take this to be a perfect agreement of normality of functions. Therefore only the motor (two scores collapsed into one) and hearing scores and the score on the final question of whether the child has a serious problem or not, were used for the analysis.

Results:

Table 6.5. gives the probability of agreement and the kappa coefficients of the OFR on three scores. The probability of agreement on the question about walking and/or using hands

Table 6.5 : Test - retest reliability of the OFR in 73 cases.

Question	$\bar{p}$	kappa	95% CI
Does the child have a problem in walking and/or using hands?	.97	.96	.92 - 1.0
Does the child have a serious problem?	.89	.76	.67 - .85
Does the child have a problem in hearing?	.96	.20	.11 - .29

functionally was 97% and the kappa score was .96. Both scores were almost perfect. The probability of agreement on hearing problems was 96%, ie. almost perfect agreement, but with kappa scores in the 'fair' range (.20). The probability of agreement on the final question of whether the CW thought the child had a serious problem or not was almost perfect (89%), with kappa scores in the 'substantial' category (cf. fig. 3.5).

The inter-observer reliability:

One hundred and one children were scored on the OFR simoultaneously by the same CW. One CW (CW2) was the constant simoultaneous scorer for all children, while any one of the others administered the test. The distribution of scòres show most of them to be almost perfect in agreement. The possibility that the CWs could have consulted each other before scoring could not be ruled out! Only the last question (OFR37) seemed to have different answers or points of view. **Table 6.6.** gives the probability of agreement on this question (96%) and the

Table 6.6 : Inter - observer reliability of the OFR (n = 101)

Question	$\bar{p}$	kappa	95% CI
Does the child have a serious problem ?	.96	.87	.80 - .94

agreement beyond chance (kappa= .87). Both scores were almost perfect.

Conclusions on the reliability tests:

1. The overall agreement on both tests was good.

2. In the test retest reliability, the coefficient of agreement was good for motor functions, substantial for the opinion of the CW on the overall functions and poor for hearing functions.

3. The inter-observer reliability scores were good for the overall functions. Others scores had perfect agreement which was slightly suspect and not included in the analysis.

4.Discussion:

This part of the study was an extension of Part A, where the 'Observation of Function' was found to be a useful adjunct to the neurodevelopmental assessment. To try out its usefulness when used by CWs was a logical sequelae, given its briefness and ease of administration, and greater implications for CBR.

At the outset the results were less forthcoming, revealing interesting aspects only by default. That is, in the absence of strong positive results, it was interesting to search for the reasons for such results. Several pertinent aspects regarding field testing of procedures by CWs were found.

For reasons of clarity, this section will be elaborated under the following headings:

1. Characteristics of the study population.
2. Structure of the OFR.
3. Characteristics and traning of the CWs.

4.1. Characteristics of the study population:

The original OF was designed and conducted for a population that differed from the study population on whom the OFR was done. The differences might have been important enough to effect the results of this study, and also the conclusions drawn.

Every child was almost a year older. From discussions in the previous chapter it was established that the OF was stretching itself in the older age groups for functional impairments. Therefore it would probably do worse for an older age group as might have been demonstrated in this study. Allowances should have been made for this fact during the structuring of the OFR.

Every child seen had all been assessed by the professional team during the original study. All children with impairments (such as night blindness, otitis media, chest infections, etc.) had been given treatment. All children with disabilities (such as post polio paresis, deafness, talipes, etc.) had had some kind of intervention (such as referral to an orthopaedic hospital for talipes, treatment of epilepsy, advice to mother on teaching daily living skills, etc.). Discussions with mothers had included general health, hygiene and sanitation, nutrition and immunisation.

The positive effects of these interventions, however rudimentary, could have been reflected in the fact that only 35% of these children were TQP positive, compared to almost 50% in the REA study.

It is also an established fact that the majority of very young children outgrow their developmental problems, especially those related to motor, speech and language delay (Nelson and Ellenberg, 1982). The fact that very few under-five-year-olds had such problems (Table 6.2.) could have been a reflection of this fact.

Introduction of family food, more focussed care by the mother, interventions like high-potency Vitamin A, are all additional factors that have been shown to improve developmental status, and could have been the case in this study.

The total outcome of these facts is that the CWs were sent out to administer the OFR on large numbers of children who were older and probably less impaired. This made the task of the CWs in discriminating functional problems more difficult. Quick screens have been shown to be more difficult when the prevalence of the problems under survey decreases (Shrout and Newman, 1989).

4.2. Structure of the OFR:

The three major characteristics which the OFR was judged to possess were that it was brief; it was criterion-referenced; and it was functional. Whilst each characteristic had its merit when used by physicians, all of them could be criticised in the context of their use by less trained

personnel.

Conciseness in recording histories, physical examination, and even developmental assessments, is an expertise that is acquired by physicians over years of training and practical experience (cf. Section 7, Chapter 1). Even then errors of judgement due to lack of time and experience are not uncommon. To make brief tests work in field settings using CWs and assuming they will be able to detect problems in such short time and in the same manner as physicians, may have been too ambitious.

The technique of rapid assessment of illnessess and psychosocial parameters by CWs is a new and successful phenomenon, which has provided public health workers new dimensions to identifying problems within the community in developing countries (Chambers, 1980; Scrimshaw and Hurtado, 1987). The concept of Rapid Assessment Procedures (RAP) was developed for the United Nations University Research Program in order to improve understanding of the successes and problems related to the implementation of the recommendations of the Alma-Ata Conference. They have since been used to collect information about varied numbers of topics in PHC such as diarrhoeal diseases, acute respiratory infections, perceptions and use of immunization etc (WHO, 1980c; WHO, 1990). High risk pregnancies are being recognised by traditional birth attendants with similar easy and quick methods (Bhargava, 1987). Psychosocial parameters for rapid assessments of environmental pollution are being outlined.

A quick and objective assessment based on quantifiable signs in the case of disability, is a more difficult task. More time to assess may have improved the sensitivity of the test as more functions could then be observed. A brief annotative account attached to the test might also have been more helpful in giving a comprehensive picture about the child. However, none of these modifications would have kept the OFR brief.

The second claim of the OFR was that it was criterion-referenced, in that all children performed the same set of procedures, and were scored on the observers' internal criterions of age-appropriate functions. This aspect of the test again assumed that the CW did have such an

internalised model or profile of normal and abnormal development within him/herself. But one may question this assumption. Without the basic substrate of knowledge about the body, growth and development, and psychological and behavioural aspects of development, can a person be expected to observe abnormal functions relative to the child's age? O'Dempsey (1988) describes examples of teaching CWs who wanted to know the 'truth' about diseases. Not unexpectedly, only children with the most gross and obvious motor impairments, and those with multiple problems affecting these gross functions, were identified.

On the other hand, criteria are relative to the person's life experiences and give a more candid impression to the observer about the child (Baine, 1988). An unadulterated version of the OFR was at least able to discern what, according to the observer, the child could do. A stress on abilities rather than disabilities has been practised and advocated by Werner (Werner, 1987).

The OFR looked at function, rather than each part of the body separately. Implicit in this approach was the notion that this was a more natural way of looking at a child compared to the clinical approach, and in this study was carried out in the child's natural environment. The previous chapters revealed that motor functions and multiple problems associated with hearing functions were the two areas best picked by the OF. The three seriously disabled children identified had similar problems. Of the other three that it missed, one had post polio paresis of one leg, and the other two had serious speech problems, one with mild MR. It can be argued that perhaps these children who were not identified were not seriously disabled according to the norms of villagers. Another plausible explanation questions the diagnosis of serious speech problems in clinical settings, when perhaps the child had performed better (expressed more with language) at home. Thus locally perceived needs of the community have to be determined (Arnold, 1986; Werner, 1986), which will in turn influence the criterions of normality and abnormality with which each person will judge a child.

4.3. Characteristics and training of the community workers:

The inherent characteristics of the CWs must be examined as these might have influenced test results, and might point to directions for future work using CWs to help identify disabled children in their community.

The test retest and inter-observer reliabilities were good, which indicates that no matter how little or how limited the CWs perceptions of abnormal/normal functions were, they were consistent and repeatable.

Given the field work done by CWs in the REA study, as well as the experience gathered in working with physical and mentally disabled children using materials from the WHO/CBR manual, one would have certainly expected them to pick up more children. Why didn't they? Was it a basic fault in the OFR that was only looking for crude functions such as walking, squatting, etc? That is a strong possibility. It is also possible that the training of CBR workers concentrates on specific physical tasks, to the exclusion of, eg. visual behaviour and communication and of child development in general.

The reliability scores indicates that the CWs should be given a more thorough training on normal and abnormal child development to improve their observational skills. The saying that 'the eyes do not see what the mind does not know' seems to be apt in this situation!

In evaluating the failure of TBA programmes, Jordan (1989) writes that 'TBAs tune out since the matarial is presented in a manner that is not familiar to them, with an emphasis on definitions, inappropriate content, and with disregard too for differences not only in literacy, relative to words, but also in visual literacy (drawing, illustrations), and of basic world views. Perhaps most importantly the TBA's own knowledge and practice is often disregarded and sometimes dismissed as of no consequence. True reciprocal teaching, the notion that midwives have something to teach the medical staff, is unthinkable within the hierarchical framework'.

More appropriate training, teaching, and not least 'learning' skills are required for the facilitators, in what is generally known as 'training of trainers', if science is to be imparted fruitfully.

5.Conclusions:

The initial results of the OFR in identifying disability were not satisfactory, as only 15% and 42% of 'all' and 'seriously' disabled children were identified, mostly with isolated motor problems (polio) or multiple disabilities with a hearing component to it. The observers were reliable in their assessments. It was argued that observing children in their natural environments could bring out their best functions, specially communication (speech disability did poorly in the OFR), and perhaps represented the true picture of disability (or ability). Briefness of the test could have been another negative factor. The scoring was based on the CWs internalised perceptions of normality/abnormality. Expecting them to have the same inner profiles as experienced physicians may be to ambitious. There is future scope for looking at the CWs' perceptions of disabilities and correlate them to medical criterions, for prioritising those children who should be given rehabilitation. There was much scope for improving/developing the CWs' knowledge about child development in general and specific development in particular. Finally, although the OFR could not be used per se in any stage of the identification process, there was scope for improving, modifying and enlarging it for future use.

CHAPTER SEVEN

Conclusion

Introduction

This chapter summarises both parts A and B of the study and discusses the implications for future work with disabled children in developing countries. The content and potential value of the study lies in the fact that it was part of, and evolved from, a field survey of disabled children aged two to nine years conducted in five sites within Bangladesh. Thus results from the study suggested both general implications on developmental screening and assessment, and significant variations dependant on such factors as site (ie. urban or rural), age of the child, mother's awareness and perceptions, etc.

The chapter will sum up the salient findings in terms of the study aims (Section 1), importance of the mother's history (Section 2) and the limitations of the study (Section 3); the scope for modifications of the OF for its use in varying contexts (Section 4); and implications of the study for future work , both in practice and in research (Section 5).

1. Salient findings of the study:

There were three specific aims of the study, of which the first two were well achieved in the results. Although the study fell far short of accomplishing the third aim, important insights were gained into the strengths and weaknesses of the utilisation of community workers as important agents in working with disabled children in rural areas.

Salient findings pertaining to each aim of the study are given below.

1.1. The **first aim** of the study was to develop a brief and functional method of identifying disabilities in general and motor disability in particular, validly and reliably, within the neurodevelopmental assessment. The findings are enumerated below.

(a) The OF identified almost three-quarters of disabilities of all grades of severity. It

differentially identified motor problems most accurately, followed by problems of cognition and speech. It did not do as well in identifying hearing and vision problems.

(b) Serious motor disability was identified universally in all children, irrespective of age, gender or site.

(c) Serious grades of disability were also identified in large numbers in the other domains, especially speech and cognition. Mild problems were more likely to be missed in these domains, particularly in the older children.

(d) It did better in identifying children with multiple problems in contrast to those with isolated disability. This was especially so for cognition. Almost all children identified in vision and hearing domains had more than one disability.

(e) The predictive values of the procedure indicated that it was best used in children at high risk of disability (ie. specifically, children who were positive in the screening questionnaire), than in the general population.

(f) The value of using it within a decision-making tree in the neurodevelopmental assessment was valid insofar as it would reduce the numbers of children who were to be neurologically examined substantially, thus saving time of the physicians to concentrate on a smaller number of children.

1.2. The **second aim** of the study was to verify whether the OF could screen for those children who did not require the neurological examination. The findings pertaining to this aim are enumerated below.

(a) A very small percentage of children who did not require the neurological examination theoretically (ie. were passed both by the mother's history as well as the OF) were diagnosed as having a disability. None of them were motor in nature. Only a few had positive signs on the neurological examination, which were nonspecific and did not add to the final diagnosis.

(b) Of the children who theoretically required the neurological examination (ie. who failed the mother's history and/or the OF), the children who failed both categories were the ones with

the most positive signs on the neurological examination. All serious motor disabilities were in this category. The neurological examination also contributed to the specific diagnosis of the underlying cause of these children's disabilities.

1.3. The **third aim** of the study was to verify whether the OF could be used by community workers in field work to identify functional problems reliably and validly. The findings from this aspect of the study are given below.

(a) The community workers did poorly in identifying problems. The few that they did identify were problems of motor and speech functions. However, half the children scored had a disability, ie. the positive predictive value was high. The poor rates of identification was attributed to inadequate training and poor theoretical knowledge about developmental problems.

(b) The test-retest and interrater reliability coefficients were high, implying that whatever was perceived as a problem was done so consistently. This indicated the potential scope of community workers to observe for disability, subject to better training in developmental theory as well as in practice.

2. There was one important **additional finding** from the study. This was the accuracy of the mother's history regarding problems in the child. Special points pertaining to this aspect of the findings are enumerated below.

(a) When a general score was considered (ie. positive on any one domain in the mothers history and correlated with diagnosis), 87% of all disabilities and 95% of serious disabilities were identified by mothers. However, the false positive identifications were high, almost 40% of normals being labelled falsely to have a disability. However many of these children had impairments or milder health problems.

(b) When a domain-specific score was considered (ie. positive on any specific worry and correlated with specific diagnosis) the mothers were highly accurate in picking up most motor

and speech problems, three-fifths of hearing and vision problems and almost half of the children with cognitive problems. Information from the mother also reduced the number of false positives significantly, and thus was invaluable in focussing upon specific functions for thorough evaluation.

(c) The function-specific scores identified serious disabilities accurately in most children. The domains that were not identified with accuracy were serious cognitive and hearing disabilities, which were identified in half and three-quarters of the children respectively.

Conclusions from these results are that mothers, irrespective of their social and educational status, may be regarded as the best reporters of their children's problems. The children they overidentify usually have some related health problem, if not impairment and disability. The OF and other such techniques can only be used as an adjunct to the mother's history or to the screening questionnaire, depending on the purpose of the assessment. Whether the reports vary according to who the interviewer is, either physician or community worker, needs verification. Initial analysis of the REA study suggests that the mothers do differentially confide and divulge more information to doctors than to community workers especially regarding socially stigmatising conditions like epilepsy (Dixit, 1989). Further analysis of the REA study is expected to provide more insights. The social barriers that prevent mothers from confiding to the community workers, who are their social peers, need to be considered and studied in future, as this would have important bearings on population based screening techniques.

3. Limitations of the study:

As this study was an off-shoot of a large scale survey of childhood disability, there were certain unavoidable limitations in the study design; for the same reason subsequent problems that arose during the field work had to be dealt with in an ad hoc manner; some of these procedural decisions later proved to be less productive; and assessing children on site came with its own difficulties and shortcomings. Most of the limitations of this study arose from these causes and are discussed below.

3.1. Limitations in the planning for the study:

More emphasis and detail should have been put into the **piloting of the OF**. The venue for both training and piloting should have simulated the field situation in which the study was conducted, instead of a special school for disabled children. It seems likely that this would have made the doctors more confident about the procedure, and also increased the inter observer reliability. Observation techniques should have been discussed in more depth. These are well established in the field of medical anthropology (Scrimshaw and Hurtado, 1987), and could have increased the sensitivity of the physician to details in the mother-child interaction such as eye-to-eye contact, tone of voice, touching, use of space (physical isolation), etc. These details could have revealed the covert disabilities more than was the case in the study. It is felt that this aspect of preparing for the study was overlooked with the typical complacency of physicians regarding the use of 'simple' methods that do not require much technical expertise. This study has proven that such is not the case, and that to observe keenly is an art that needs perfecting and one that may yield gratifying results.

During analysis the **lack of descriptive notes** on the children was also felt to be a serious limitation, insofar as subtle aspects of the child's disability and environment was concerned. All details of the neurodevelopmental assessment was in coded questionnaire form (MAF). Although in large surveys such quantitative information is more objectively verifiable and scientifically respected, it also excludes qualitative information about functioning, excluding all phenomena other than the more physical (Hougenhougen and Draper, 1990). Had more annotative information been available, the uncertainties regarding mild disabilities, impairments and the extreme ends of 'normality' could have been sorted out, especially in the younger study children. This might also have prevented the age bias that was seen within the OF. Another valid criticism of the MAF is that by adhering to the **biomedical model of assessment** it lost out on the unique information that could have been collected regarding the social aspects of disability, such as stress on the family, mother's attitudes, relationship with siblings, etc. - all of which require more open-ended and conversational approaches. As the

assessments were done in the children's natural environment, all of the open-ended answers could have been compared with the examiner's direct observations. It would have gone a long way toward answering unresolved questions as to the normal developmental course of children and child rearing norms in villages and inner cities; what is 'functional' for a particular age group; whether differentially some disabilities are more burdensome than others in specific communities; what stress is felt by family, and lastly the older children could have been asked directly about their problems. Given these drawbacks in the MAF format, it must be said that large numbers of children could be examined by using it, information thus retrieved being objective and as true to reality as possible for the child, at that point in time.

It was also felt that regarding the second part of the study better **training of the community workers** and more intense **piloting of the QFQ** would have given better results. Some insights into the CWs' perceptions of the children's functioning should have been obtained at this stage, which might have taught the trainer something about priorities given to disabilities within the local context. There was also a sense of complacency on the part of the trainer, secure in the knowledge that the CWs were all involved with disabled children for over a year and would thus be able to identify problems. From the results which ensued it became clear that theoretical knowledge should have been provided alongside practical demonstrations, to improve upon the CW's 'internalised model' of normal child development.

3.2. Limitations during field work:

Field conditions were far from the ideal 'clinic situation' for carrying out neurodevelopmental assessments. It was felt that they carried a substantial limitation in the assessment of each child. Although it was the natural enviroment for the children, it was **not the natural environment for assessments** with which physicians were familiar although one could conclude that this demands expertise that every physician working in developing countries should acquire! The **venue** of assessment varied every day (eg. open courtyard of a homestead or schoolroom). Much **time** was spent performing mundane tasks, such as getting

all the medical instruments (tape measures, stethoscope, diagnostic sets, toys, etc.) out of bags, and arranging for anthropometric measurements, vision tests (distances) and determining the screening cut-offs for the day on the audiometer. Distractions were offered in the form of crowds gathering around the examining area (which can be intimidating even to the most hardened physician working in busy outpatient clinics in inner city hospitals). Often children with health problems who were outside the study were brought with for examination, which was usually not refused, although they were asked to wait. Deadlines for finishing work would be imposed on the team due to poor road conditions, rivers that needed to be crossed by ferry, etc. If the assessment was carried out at home, care was taken to socialise with the family, which was also informative[1].

Human errors arising from having to make many quick judgements must be taken into account. From this point of view, the value of the OF in excluding functionally normal children from the neurological examination was increasingly appreciated by both physicians as the study progressed.

The above constraints also contributed to the small number of children on whom **reliability** studies were done. It was difficult to go again to all sites; and for both observers to simultaneously observe also meant that there was less time available for each of them. However, for the study it seems in retrospect that had more time been spent in discussion between the two physicians, it might well have improved inter-rater reliability, as well as the validity of the OF.

---

[1]I spent a substantial amount of time walking through the village or locality observing local habits, cooking practices and the role of women in the community, talking to traditional birth attendants, and generally absorbing the qualities of social life in the community that one can only subjectively experience. I have never felt closer to my people than during the field study of this research. Despite the positive nature of the experience, however, all aspects contributed to the difficulty of making the assessment of each child. There was a whole form to fill, and a valid estimate of the child's disability to make, all in limited time.

3.3. Additional considerations in doing neurodevelopmental assessments in field situations:

Most of the scientific limitations have been mentioned above. There is an additional factor to be discussed, which is a limitation of any study which seeks to identify health problems in a general population. Given all the environments in which the assessments were conducted, the easiest data to record were the aspects of assessment the physicians felt most comfortable about, ie. treatable conditions where the obvious medical needs were met (eg. antibiotics, Vitamin A capsules, or treatment for skin infections). Nutrition and food habits were discussed with every mother as was sanitation and drinking of safe water. However, when a child with a substantial disability was assessed, ethical considerations immediately came into focus. The notion of identifying a disability without offering rehabilitation is a potentially volatile ethical issue, the merits and demerits of which could be argued unendingly. This was most obvious where a seriously motor disabled child who needed physical therapy or ambulatory aids was concerned. The CWs would take the mother and child aside to show practical methods of carrying, playing, etc. However, this was not adequate and the problem remained unresolved. In the long run this limitation seemed not to have a deleterious effect on the family especially the mother, as evidenced by the warm welcome the research team received when part B of the study was done a year later.

The possibility of a positive 'study effect' that benefits the disabled child in the long-run has been touched upon in epidemiological studies conducted in developed countries (Davies et al, 1972). Nikapota and co-workers in Sri Lanka, working with mental health in children, maintain that there is a crucial interface between the mother and the child on which depends the quality of care that the latter receives (Nikapota, 1985). This improves with increased knowledge in the mother about the various aspects of child development. It seemed likely to the study team that mothers with a seriously disabled child, and even those with children with other health problems, gained in confidence from talking about the problem. These notions need to be verified in a more concrete and scientific manner.

4. Scope for future modification of the OF:

There are several ways in which the OF can be modified or adapted for future use, depending on the personnel who use it and the reasons for which it is being used. From insights derived from this study the possible kinds of modifications that can be made of the OF are discussed below, divided into two sections - that is, use by physicians and use by intermediate health care workers or community workers.

4.1. Modifications of OF - for use by physicians:

It is assumed that physicians will use the OF in the context of the full neurodevelopmental assessment. In what contexts such assessments are done will also determine the kinds of changes to be made. The various contexts for use are discussed in the next section. The possible changes elaborated below are discussed generally and may be applicable to all or some contexts of usage.

4.1.1 Tasks could be graded:

If milder problems are to be identified the OF needs to be changed so that the tasks are more specifically graded by age. The propensity of the OF to miss **more mild forms of motor disability** in older children (ie. five years to nine years) could be improved by providing tasks for this group which are more difficult and also age appropriate. This would increase its face validity for the older age group. For instance, these children could be asked to climb steps or a steep path, a function all rural children are expected to perform as the homesteads are on raised high ground with sometimes quite high steps to climb. For urban children portable steps could be used. Similarly, identification of **mild speech, language and comprehension problems** could be improved, for example, by asking about what could be bought with a coin from the local bazaar.

4.1.2 Improve sensitivity for vision and hearing functions for all age groups:

Hearing impairments can be made more identifiable by using the same commands as were originally used, in this case said from behind the child so that he/she cannot see the examiner. The concept of the Cooperative Test can be thus adopted. Mild visual problems are more difficult to assess within a single task, except that the objects on the ground can be made smaller, placed further away, and care taken not to give away the specific spot where they are placed.

4.1.3 An extra score on the 'alertness' of the child?:

The 'insurance factors' elaborated in Chapter 5, such as the attentiveness, interest, alertness, friendliness, and mother-child or peer relationships of the child have been established to be a crucial part of the entire development and motivation of the child, no matter how able or disabled (cf. Bayley). This be scored in the OF. It is felt that it would provide a valuable addition to the 'developmental profile'.

4.1.4 Some extra functional assessments based on mother's history?

- **a focussed approach:**

Since mothers provided the vital information for most children and their developmental functions, specific problems mentioned could be focussed upon when doing the OF and as an adjunct to it. For instance, if the complaint is about motor problems, after getting an overview of functions with the OF, extra tasks can be given to the child, such as threading a bead, playing ball, hopping, standing on one leg, etc.

4.1.5 Annotations:

Some factors that go beyond the scope of the OF but are essential to function can be described in the form of short notes. The child, for instance, could be walking without support and be functional, but the gait might be such (for example a child with post polio shortening of

the leg with marked pelvic tilt) that it is predictive of future deformities. This could be put as a comment. Similarly, notes could be made about other 'at risk' features in a functionally 'normal' child, such as the child who has a squint, or looks very malnourished.

4.1.6 Scoring behaviour problems:

This is an aspect that was not focussed upon in the study, although there were a few questions within the history section and a scoring category in the final diagnosis (which was excluded from analysis). Mental health in children has been studied in Sri Lanka and the reports on interventions with mothers and children seems positive (Nikapota, 1985). But can a short observational procedure identify behaviour patterns? - that is more difficult to answer. Integrated health programs that focus upon increasing the well-being of the child rather than the treatment of mental health problems has been emphasised (Graham, 1982). However, observational techniques are established means of assessment used in child psychiatry (Graham, 1989) and if the constraints of time and limited settings are removed, has a scope for incorporation into the procedure.

4.1.7. Can infants be included?:

As we know, the earlier a child is detected for developmental problems, the better is the chance of amelioration and secondary prevention. The new-born has observable functions that are used in evaluation, diagnosis and future prediction (Apgar, 1953; Dubowitz and Goldberg, 1970). Is it not possible to extend our observations validly and reliably to encompass infants in field situations? - since that is where they are born and nurtured. High risk infants are being identified in developing countries by traditional birth attendants (Mangay-Maglacas and Pizurki, 1986). The lessons from such studies could be learned and positive functional signs incorporated into the procedure.

4.2. Modifications of the OF when done by CWs:

Although the results from the present study are not encouraging there are still positive aspects which can be extracted for the future.

All the suggestions for modifications within the OF mentioned in the previous section are applicable here too. In this case the most important factor is **training and teaching of the CWs to observe**. As has been mentioned in Section 3, this is a technique and an art that has to developed by the trainers of CWs. Every CW could be trained to assess the functional abilities of every child they screen (eg. on the TQP) and to rehabilitate them (eg. using WHO manuals). The concept of functional assessment would provide the CW not only with information about the abilities of the child, but also with a basis for teaching functional tasks (Baine, 1989; Serpell, 1991).

The **'anthropological approach' of observation**, which encompasses not only the child but also the people and the environment, also seems tenable. While the REA study compiled putative risk factors for disability along with the TQP itself, there is much to be said for directly observed accounts of such aspects as the state and resources of the household, relationship between siblings, mothers' sociability, and mother-child or father-child relationships. These techniques have been widely used by CWs in medical anthropology for studying subjects like eating habits and breast feeding trends, sanitation and parasitic diseases, protein-energy malnutrition, child morbidity and mortality, etc. (Becker et al, 1986; Cassel, 1977; Cassidy, 1982). As impairment and disability form a part of, as well as resulting from, the unique cultures in which they exist, such an approach could go a long way toward giving indications of the cultural and social milieu in which the affected children live and are expected to survive, and with what amount of nurturing. This quality of information will not only help the CW in devising and suggesting individualised programme planning (IPP) (Serpell, 1991) for a child in relation to his/her home, but also reveal the strengths and weaknessess, attitudes and superstitions, and priorities and prerogatives of the community. Furthermore these could go a long way toward helping programme planners rearrange priorities in working with the

disabled at the level of both the individual and society.

5.Implications for future work:

The implications of this study for future work can be divided into two main categories: ie. research purposes and clinical work. Both aspects are considered.

5.1. Implications for research:

As a tool to be used in **neuroepidemiology**, the OF has been proven to be useful, saving time for the physicians and giving a idea about every child's comprehensive developmental profile within the task. It could be used as it is, without any change, in large scale surveys where comprehensive neurodevelopmenal assessments need to be done, provided the caveats mentioned in discussion of the study results are heeded.

It may also be used in **other field surveys and epidemiological work** in any aspect of primary health care and public health that look at health parameters in children (eg. the Goitre Prevalence Survey, Survey for Nutritional Blindness); or in health surveillance programmes that are more longitudinal such as growth monitoring in under-five clinics. If CWs are the key facilitators in these programmes the value of the procedure may be best used together with a screening questionnaire such as the TQP.

In **Community Based Rehabilitation (CBR)** the OF would have to be viewed by the facilitating agent (whether CW, mother, therapist or physician) as a theoretical blend of 'profile referenced' and 'criterion referenced' testing. The former would be evaluative and the latter rehabilitative, ie. act as a guide to intervention.

These possibilities for use of the OF in future research would need to be tested out. Small scale piloting within existing programs could be the ideal way of practically demonstrating what it espouses.

5.2. Implications for practice :

Clinical work in developing countries is characterised by large attendance of children, whether it is in a **general city hospital** or a **community based maternal and child clinic** in outreach areas. The quality of examination is severely hampered when the child has to be seen within five minutes. Neurological examinations have a low priority unless warranted by gross neurological signs and symptoms (eg. neck rigidity or drowsiness). In such circumstances the potential value of the OF seems to be indicated. It is in no way proposed as an alternative to the NE but only as a screen for those who need it. All physicians as well as medical students could be taught the procedure and its underlying developmental implications and this would help to provide a more holistic approach to evaluating a child's functional abilities.

As neurodevelopmental assessment itself is a fairly new practice for physicians in countries such as Bangladesh, one would hope that practically tested, simple methods such as the OF would be easier to incorporate and provide practical help to the physician, so that the best possible use is made of the physician's time with maximum benefit to the child, in the short as well as the long term.

REFERENCES

Ades AE (1990) Evaluating screening tests and screening programmes. Arch Dis Child. 65: 792 - 795.

Alberman E (1984) Epidemiological aspects of severe mental retardation. In: J Dobbing, ADB Clarke, JA Corbett, J Hogg, RO Robinson (1984) Scientific Studies in Mental Retardation. London: Royal Society of Medicine and the Macmillan Press Ltd.

Apgar V (1953) A proposal for a new method of evaluation of the newborn infant. Curr Res Anesth Analg. 32: 260 - 267.

Arbab F (1984) Development, a challenge to Bahai scholars. Bahai Studies Notebook. 3: 1 - 19.

Armitage P, Berry G. Statistical Methods in Medical Research. 2nd. ed. Oxford: Blackwell Scientific Publications.

Arnold C (1986) Reaching families in rural areas. Paper presented at the 9th International Conference of the International League of Societies for persons with Mental Handicap (ILSMH), Rio de Janerio, Brazil.

Bachani D, Singh MP, Yadav S, Pawar RG (1983) Utilisation of the preventive services - an elaborative study of vaccine acceptors. Indian Journal of Preventive and Social Medicine. 14: 35 - 41.

Bagnato SJ, Neisworth JT, Eaves RC (1978) A profile of perceived capabilities for the preschool child. Child Care Quarterly. 7: 327 - 335.

Baine D (1988) Handicapped Children in Developing Countries: Assessment, curriculum and instruction. Dept. of Educational Psychology, Edmonton, Canada: Vector.

Bairagi R (1980) Is income the only constraint on child nutrition in rural Bangladesh? Bulletin of the World Health Organization. 58: 767 - 772.

Bairagi R, Edmonston B, Awal Dad Khan (1987) Effects of age misstatement on the utility of age - dependant anthropometric indicators of nutritional status in Bangladesh. Am J Pub Health. 77(3): 280 - 282.

Baird, Gordon (1983) Neurological Examination of Infants and Children. CDM series nos. 84/85. Spastics International Medical Publications.

Banerji D (1974) Social and cultural foundations of health services-systems. Economic and Political Weekly, special no., 1333 - 1346.

Bayley N (1969) Bayley Scales of Infant Development: Infant Behaviour Record. New York: The Psychological Corporation.

Balasubramanyan V (1991) India: Protests over salt iodization. Lancet. 337: 226.

Bax M, Whitmore K (1987) The Medical Examination of Children on Entry to School. The Results and Use of the Neurodevelopmental Assessment. 29: 40 - 55.

Becker S et al (1986) Relations between socio-economic status and morbidity, food intake and growth in young children in two villages in Bangladeh. Ecology of Food and Nutrition. 18: 251 - 264.

Belcher DW, Nicholas DD, Ofosu-Amaah S, Wurupa FK (1978) A mass immunization campaign in rural Ghana - factors affecting participation. Public Health Reports. 93: 170 - 176.

Belmont L (1984) The International pilot study of severe childhood disability, final report. Utrecht, Netherlands. Bishop Bekkers Institute.

Belmont L (1986) Screening for severe mental retardation in developing countries: The International Pilot Study of Severe Childhood Disability. In: Berg JM (ed) Science and Service in Mental Retardation. London: Methuen. 386 - 395.

Bennett FC, Guralnick MF, Burtt Richardson H, Karen E Heiser (1984) Teaching Developmental Pediatrics to Pediatric Residents: Effectiveness of a Structured Curriculum. Pediatrics. 74(4) : 514 522.

Beran RG, Michelazzi J, Hall L et al (1985) False-negative rate in epidemiologic studies to define prevalence ratios of epilepsy. Neuroepidemiology. 4: 82 - 85.

Bhargava Indria (1987) (ed) Task fource on maternal mortality and morbidity. Ministry of Health and Family Welfare. Govt. of India, New Delhi.

Bhuiyan A, Wojtyniak B, D'Souza S, Nahar L, Shaikh K (1987) Measles case fatality among the under-fives: a multivariate analysis of risk factors in a rural area of Bangladesh. Social Science and Medicine. 24: 439 - 443.

Bishop D, Rosenbloom L (1987) Childhood Language Disorders: Classification and Overview. In: William Yule and Michael Rutter (eds) Language Development and Disorders. Oxford: MacKeith Press.

Blair E, Stanley F (1985) Interobserver Agreement in the Classification of Cerebral Palsy. Dev Med Child Neurol. 27: 615 - 622.

Bleck E (1979) Orthopedic management of cerebral palsy. Saunders monograph in clinical orthopedics. Vol II. Philadelphia: W.B.Saunders.

Bloch AB, Orenstein WA, Wassilak SG, et al (1986) Epidemiology of measles and its complications. In: EM Gruenberg (ed) Vaccination against Brain Syndromes: the campaign against measles and rubella. Oxford University Press.

Boucebci M (1981) Special Education through neighbourhood centres in Algeria. Assignment Children. 53/54: 153 - 163.

Brett EM (1991) Paediatric Neurology. 2nd ed. London: Churchill Livingstone.

Brink, Edward W, Parera, Davey A, Broske, Stuart P (1979) Vitamin A status of children in Sri Lanka. Am J Clin Nutr. 32: 84 - 91.

Brown KH, Gaffer AA, Sharif M (1979) Xerophthalmia, protein-calorie malnutrition, and infection in children. J Trop Ped. 95(4): 651 - 656.

Bryant J (1979) Principles of justice as a basis for conceptualizing a health care system. Int J of Health Services. 7: 707 - 719.

Capute AJ, Biehl RF (1973) Functional Developmental Evaluation. Ped Clin North Am. 20: 3 - 26.

Cassel J (1977) Social and cultural implications of food and food habits. In: D Landy (ed) Culture, Disease and Healing, Ch. 26, pp 236 - 242. London: Macmillan.

Cassidy C (1982) Protein energy malnutrition as a culture-bound syndrome. Culture, medicine and psychiatry. 6: 235 - 245.

Chamberlain G, Banks J (1974) Assessment of the Apgar Score. Lancet. ii: 1225 - 1228.

Chamie M (1986) Development of statistics of disabled persons: case studies. United Nations Department of International Economic and Social Affairs, Statistics on Special Population Groups, Series Y, No. 2, New York: U.N.

Chambers R (1980) Rapid Rural Appraisal: Rationale and Repertoire. Institute of Development Studies, Brighton.

Chen CC (1989) Medicine in Rural China. A personal account. California: University of California Press.

Cohen J (1960) A coefficient of agreement for nominal scales. Educational and Psychological Measurement. Vol XX., No. 1: 37 - 46.

Cohen N, Rahman H, Sprague J, Jalil MA, Leemhuis de Regt E, Mitra M (1985) Prevalence and determinants of nutritional blindness in Bangladeshi children. World Statistics Quarterly. 38: 317 - 330.

Cohen MA, Jalil H, Rahman E, et al (1986) Blinding malnutrition in rural Bangladesh. J Trop Pediatr. 32: 73 - 78.

Conley RW (1973) The Economics of Mental Retardation. Baltimore, Johns Hopkins University Press. p. 40 - 42.

Cooper ES, Costello AJ, Douglas JWB, Ingleby JD, Turner RK (1974) Direct Observation?. Bull Br Psychol Soc. 27: 3 - 7.

Coplan J (1987) Deafness: Ever Heard of it? Delayed Recognition of Permanent Hearing Loss. Pediatrics. 79(2): 206 - 213.

Cravioto J, Robles B (1965) Evolution of adaptive and motor behaviour during rehabilitation from Kwashiorkor. Am J Orthopsychiatry. 35: 449 - 452.

Cronbach LJ, Glaser GC (1965) Psychological tests and personnel decisions. Urbana: University of Illinois Press.

Davie R, Butler N, Goldstein H (1972) From Birth to Seven: the second report of the National Child Development Study (1958 Cohort). London: Longman Group Ltd.

Delange FM (1972) A survey of the clinical and metabolic patterns of endemic cretinism. Adv Exp Med Biol. 30: 175.

Delange FM, Dunn JT (1987) The definition of goitre stages. IDD Newsletter. 3(1): 5.

Diaz-Briquets S (1981) Determinants of mortality transition in developing countries before and after the Second World War: some evidence from Cuba. Population Studies. 35(3) : 399.

Djukanovic V, Mach PE (1975) Alternative approaches to meeting health needs in developing countries. UNICEF/WHO.

Drillien C, Drummond M (1983) Developmental Screening and the Child with Special Needs. London: William Heinemann Medical Books Ltd.

Dubowitz V, Goldberg C (1970) Clinical assessment of gestational age in the newborn infant. J Pediatr. 77:1.

Dulberg EM (1987) An evaluation of the effectiveness of iodized oil injections in preventing endemic cretinism and milder developmental delay. DrPH Thesis, Columbia University, School of Public Health.

Durkin M, Zaman S, Thorburn M, Hasan M, Davidson L, Shrout P, Stein Z (1989) Screenig for childhood disability in less developed countries: rationale and reliability of a method using community workers. Int J Ment Health.

Durkin M, Davidson L, Hasan M, Khan N, Thorburn M, Zaman S (1990) Screenig for Childhood Disabilities in Community Settings. In: MF Thorburn, K Marfo (eds) Practical Approaches to Childhood Disabilities in Developing Countries. St. John's, Canada: Project Seredec, Jamaica: 3D Projects.

Enwemeka CS (1981) Social norms and medical rehabilitation in the developing world. Paper presented at the 7th International Conference on Social Science and Medicine, Langelaan, Netherlands.

Evans JR, Leishman K, Warford J (1981) Shattuck Lecture - Health Care in the Developing World: Problems of Scarcity and Choice. N Eng J Med. 305 (19): 1117 - 1127.

Expanded programme on immunization (1977) Survey for residual poliomyelitis - paralysis - Egypt. Weekly Epidemiologic Record. 52: 269 - 271.

Expanded Programme for Immunization global advisory meeting, Washington,DC, Nov 9 - 13, 1987. Potential contribution of the Expanded Programme on Immunization to the control of vitamin deficiency and iodine deficiency disorders.

Farber MJ, Shapiro BK, Palmer FB, Capute AJ (1985) The Diagnostic Value of the Neurodevelopmental Examination. Clinical Pediatrics.24(7): 367 - 372.

Fauveau V, Bogdan W, Mostafa G, Sarder AM, Chakraborty J (1990) Perinatal mortality in Matlab, Bangladesh: A community - based study. Int J Epid. 19(3): 606 - 612.

Flam R (1989) Screening for childhood vision and hearing disability in developing countries. DrPH Thesis, School of Public Health, Columbia University.

Fletcher RH, Fletcher SW, Wagner EH (1988) Clinical Epidemiology: the essentials. 2nd.ed. Baltimore: Williams and Wilkins.

Foster A, Sommer A (1986) Childhood blindness from corneal ulceration in Africa: causes, prevention, and treatment. Bull WHO. 64: 619 - 623.

Frankenburg WK, Goldstein AD, Camp BW (1971) The Revised Denver Developmental Screening Test: its accuracy as a screening instrument. J Pediatr. 79: 6.

Fryers T (1981) Problems for screening for mental retardation in developing countries. Int J Mental Health. 10(1): 64 - 75.

Fryers T (1986) Screening for developmental disabilities. In K Marfo (ed) Childhood disabilities in developing countries. New York: Praeger Publishers.

Gardner M, Altman DG (1986) Confidence intervals rather than P values: estimation rather than hypothesis testing. Br Med J. 292: 746 - 750.

Gesell A, Amatruda CS, Castner BM, Thompson H (1939) Biographies of Child Development. London: Hamish Hamilton.

Gesell A (1940) The First Five Years of Life. New Yok: Harper and Row.

Gish O (1981) Health and Family Planning Services in Bangladesh: A study of Inequality. Int J Health Serv. 11 (2).

Glascoe FP, Altemeier WA, Maclean WE (1989) The Importance of Parent's Concerns About Their Child's Development. 143: 955 - 958.

Goodwin S (1990) Children With Special Needs in England and Wales: the Care of Hearing Impairment, Myelomeningocele, and Adolescent Pregnancy. Pediatrics. 86(6): 1112 - 1116.

Goldkamp O (1984) Treatment effectiveness in cerebral palsy. Archives of Physical Medicine and Rehabilitation. 65: 232 - 234.

Graham P (1982) Possibilities of prevention. In: PJ Graham (ed) Epidemiological approaches to child psychiatry. London: Academic Press, 1977.

Grant J (1984) The State of the World's Children. Oxford, U.K.: Oxford University Press.

Grant J (1988) The State of the World's Children, 1988. New York: Oxford University Press.

Grant J (1991) The State of the World's Children 1991. New York: Oxford University Press.

Gubbay SS (1975) The Clumsy Child. A Study of Developmental Apraxia and Agnosic Ataxia. London: W.B. Saunders.

Gudalefsky A (1985) Training programmes for persons who are working with the mentally handicapped. Paper presented at the 7th Asian Conference on Mental Retardation.

Gustavson K, Holmgren G, Jonsell R, Jonsell K, Blomquest H (1977) Severe mental retardation in a northern Swedish county. J Ment Def Res. 21: 161 - 180.

Haerer A, Anderson D, Schoenberg B (1986) Functional disability associated with major neurologic disorders. Arch Neurol. 43: 1000.

Hagberg B (1978) Severe mental retardation in Swedish children born 1959 - 1970: epidemiologic panorama and causative factors. In: Major mental handicap: methods and costs of prevention. Ciba Foundation Symposium 59, Amsterdam: Elsevier. p. 29 - 51.

Hagberg B, Hagberg G, Lewerth A et al (1981) Mild mental retardation in Swedish school children. I. Prevalence. Acta Ped Scand. 70: 441 - 444.

Hall DMB (1989) Personal Practice: Assessment of the slow pre-school child. Arch Dis Child. 64: 295 - 300.

Hammerman S, Maikowski S (1981) The economics of disability: International perspectives. Rehabilitation International, New York.

Hammerman S (1984) UNICEF involvement in disability prevention, early intervention programs. International Rehabilitation Review, 3rd and 4th Quarter, 9.

Haque T (ed) (1984) Report on the National Goitre Prevalence Study of Bangladesh. Institute of Public Health Nutrition. Dietetics and Food Science, Ministry of Health and Population Control, Dhaka, Bangladesh.

Harpham T, Vaughan P, Rifkin S (1985) Health and the Urban Poor in Developing Countries. London School of Hygiene and Tropical Medicine: EPC Publication Number 5.

Heggenhougen K et al (1987) Community Health Workers: the Tanzanian Experience. Oxford University Press, Oxford.

Heggenhougen K, Draper A (1990) Medical Anthropology and Primary Health Care. An Introduction and Selected Annotated Bibliography. EPC Publication No. 22, London School of Hygiene and Tropical Medicine.

Helander E, Mendis P, Nelson G (1983) Training Disabled Poeple in the Community (3rd ed). Geneva: World Health Organisation.

Helen Keller International/ Institute of Public Health Nutrition. (1985) Bangladesh Nutritional Blindness Study 1982 - 83. HKI : New York.

Herman A, Wyndham C (1985) Changes in infant mortality rates among whites, coloured and urban blacks in the RSA over the period 1970 - 1983. S African Med J. 68: 215.

Hetzel BS (1983) Iodine deficiency disorders (IDD) and their eradication. Lancet. 1983: ii: 1126 - 1129.

Hickson GB, Alteimer WA, O'Conner S (1983) Concerns of mothers seeking care in private pediatric offices: oppurtunities for expanding services. Pediatrics. 72: 619 - 624.

Hirst M, Cooke K (1988) Grading severity of childhood disablement: comparing survey measures with a paediatrician's assessment. Child: care, health and development. 14: 111 - 126.

Holborow C, Martinson F, Anger N (1981) A study of deafness in West Africa. Commonwealth Society for the Deaf Occasional Paper.

Holt KS (1957) A suggested medical classification of handicapped children. Arch Dis Child. 32: 226 - 229.

Holt KS (1981) The assessment of walking in children with particular reference to cerbral palsy. Child: care, health and development. 7: 281 - 297.

Holt KS (1991) Child Development: Diagnosis and Assessment. London: Butterworth-Heinemamm.

Hutchins PM, Foster BK, Paterson DC, Cole EA (1985) Long-term results of early surgical release in club foot. J Bone Joint Surg (Br). 67: 791 - 799.

Illingworth RS (1958) Dissociation as a guide to developmental assessment. Arch Dis Child. 33: 118 - 122.

Illingworth RS (1987a) The Development of the Infant and Young Child - Normal and Abnormal. 9th ed. Edinburgh: Churchill Livingstone.

Illigworth RS (1987b) The normal child. Some problems of the early years and their treatment. 9th ed. Edinburgh: Churchill Livingstone.

Illingworth RS (1987c) Personal Practice: Pitfalls in developmental diagnosis. Arch Dis Child. 62: 860 - 865.

International Centre for Diarrhoeal Disease Research, Bangladesh (1982) Demographic surveillance system - Matlab. Glimpse. 4 (11 - 12) : 1.

Jaffer R (1985) Report of the Community - Based Rehabilitation in district Jhelum, Pakistan, Nov 1983 - Dec 1984. Prepared for the UNICEF, Lahore, Pakistan.

Jaffer Razia and Jaffer Rafiq (1990) The WHO— CBR approach : Programme or Ideology : some lessons from the CBR experience in Punjab, Pakistan. In : K Marfo, M Thorburn (ed) Practical approaches to Childhood disability in developing countries.

Jobert B (1985) Populism and Health Policy: the case of the community Health Workers in India. Social Science and Medicine. 20 (1): 1 - 29.

Johnson A, Ashurst H (1989) Is popliteal angle measurement useful in early identification of cerebral palsy?. Dev Med Ch Neurol. 331: 457 - 465.

Johnson P, Poteat GM, Kushnick T (1986) Comparison of mental age estimates made by pediatricians and mothers of preschool children. J Pediatr Psychol.

Jordan B (1989) Cosmopolitan Obstetrics : some insights from the training of traditional midwives. Social Sciences and Medicine. 29(9): 925 - 944.

Kakar S (1982) Shamams, Mystics and Doctors: a psychological enquiry into India and its healing traditions. London: Unwin Paperbacks.

Khan NZ (1985) A study of mentally handicapped children. Aetiology and other associated factors. Bangladesh Journal of Child Health. 9 (2): 102 - 108.

Khan NZ, Zaman S, Habib S (1985) Mental retardation and other associated disabilities in children attending a Child Development Clinic in Dhaka city. Dhaka Shishu (Children's) Hospital Journal,Bangladesh. 2 (1) : 205 - 210.

King M (1966) Medical Care in Developing Countries. Oxford University Press, Oxford.

Knobloch H, Stevens F, Malone A et at (1979) The validity of parental reporting of infant development. Pediatrics. 63: 872 - 874.

Leboyer F (1977) Loving hands: the traditional Indian art of baby massage. London: Collins.

Lemeshow S, Stroh G (1988) Sampling Techniques for Evaluating Health Parameters in Developing Countries. Working paper prepared for the Board on Science and Technology for International Development, National Research Council, Washington D.C., U.S.A.: National Academy Press.

Levine RA (1980) A cross-cultural perspective on parenting. In: MD Fantini and R Ca'denas. Parenting in a multicultural society. New York: Longman.

Lindon RL (1963) The PULIBEC system for the medical assessment of handicapped children. Dev Med Ch Neurol. 5: 125 - 145.

Longstreth WT Jr, Koepsell TD, van Belle G (1987) Clinical Neuroepidemiology. Diagnosis. Arch Neurol. 44: 1091 - 1099.

Mangay-Manglacas A, Simons AJ (eds) (1986) The potential of the Traditional Birth Attendant. WHO, Offset Pub No. 95, Geneva.

Marfo K (1986) Confronting Childhood Disability in Developing Countries. In: K Marfo, S Walker, B Charles (eds) Childhood Disabilities in Developing Countries. New York: Praeger Publishers. p. 3 - 26.

Martin JB (1984) Undergraduate education in the medical specialities: the case of neurology. N Eng J Med. 311(16) : 1045 - 1050.

McConkey R (1986) Video Training in Developing Countries. Dublin: St. Michael's House.

McConkey R (1988) Out of Africa: an alternative style of services for poeple with mental handicaps and their families. Mental Handicap. 16: 23 - 26.

McCormick B (1988) Screening for hearing impairment in young children. London: Croom Helm.

McLaren J, Bryson S (1987) Review of recent epidemiologic studies of mental retardation: prevalence, associated disorders, and etiology. Am J Ment Retard. 92 (3): 243.

Menon K, Vijayaraghavan K (1980) Sequelae of severe xerophthalmia: a follow-up study. Am J Clin Nutr. 33: 218 - 220.

Mia A, Islam, Ali (1979) Situation of physically handicapped children in Bangladesh, a field survey. Dacca: Institute of Social Welfare and Research.

Milch H (1959) The measurement of hip motion in the saggital and coronal planes. J Bone Joint Surgury. 41A: 731 - 736.

Miles M (1985) Where there is no Rehabilitation Plan: a critique of the WHO scheme and suggestions for future directions. Peshawar, Pakistan: Mental Health Centre.

Miles M (1986) Misplanning for Disabilities in Asia. In: K Marfo, S Walker, B Charles (eds) Childhood Disabilities in Developing Countries. New York: Praeger Publishers.

Miles M (1990) A Resource Centre Developing Information-based Rehabilitation. In: MJ Thorburn, K Marfo (eds) Practical Approaches to Childhood Disability in Developing Countries: insights from experience and research. Canada: Project Seredec, and West Indies: 3D Project.

Miller SA, Omene JA, Bluestone CD, Torkelson DW (1983) A point prevalence of otitis media in a Nigerian village. Int J Ped Otorhinolaryngology. 5: 19 - 29.

Mittler P (1981) Finding and helping severely mentally handicapped children in developing countries: summary of discussions. Int J Mental Health. Belmont L (ed). 10(1): 107 - 116.

Monckeberg F (1968) Effect of early marasmim malnutrition on subsequent physical and psychological development. In: NS Scrimshaw and L Gordon (eds). Malnutrition, learning and behaviour. Cambridge, Mass.: MIT Press.

Moyes A (1981) One in ten. Disability and the very poor. Oxford: OXFAM.

Narasimhan M, Mukherjee A (1986) Disability A Continuing Challenge. New Delhi: Wiley Eastern Ltd.

Navarro V (1974) The underdevelopment of health and the health of underdevelopment: an analysis of the distribution of human health resources in Latin America. Int J Health Services. 4: 5 - 7.

Neligan G, Prudham D (1969) Potential value of four early developmental milestones in screening children for increased risk of later retardation. Dev Med Child Neurol. 11: 423.

Nelson KB, Ellenberg JH (1982) Children who 'outgrew' cerebral palsy. Pediatrics. 69(5) : 529 - 535.

Nelson KB, Ellenberg JH (1986) Antecedents of cerebral palsy: multivariate analysis of risk. N Eng J Med. 315: 81 - 86.

Neville B ( ) Progressive and static pathology in paediatric neurology. Medicine. 33: 1698 - 1701.

Ng'andu SK, Sinyangwe IM (1981) Final report of the feasibility study for Zambia National Campaign to reach disabled children. Lusaka: University of Zambia Educational Research Bureau.

Nikapota AD (1985) Acceptance of Intervention by parents of mentally retarded children. Ceylon J Child Health. 12 (5): 37.

Noble JH (1981) Social inequity in the prevalence of disability projections for the year 2000. Assignment Children, 53/54: 23 - 32.

Nondasuta A, Husdee R (1990) Thailand: from policy to implementation. In: E Tarimo, A Creese (eds) Achieving Health for All by the Year 2000. WHO, Geneva.

Ofosu Amaah S, Kratzer JH, Nicholas DD (1977) Is poliomyelitis a serious problem in developing countries? - lameness in Ghaanian schools. British Med Journal. 1: 1012 - 1014.

O'Toole BJ (1987) Community-based Rehabilitation problems and possibilities. European Journal of Special Needs Education. 2,3 : 177 - 190.

O'Toole B (1989) The relevance of parental involvement programmes in developing countries. Child: care, health and development. 15: 329 - 342.

O'Toole B (1990) Community-Based Rehabilitation: the Guyana evaluating project. In: MJ Thorburn, K Marfo (eds) Practical Approaches to Childhood Disability in Developing Countries. Jointly published by: Project Seredec, Newfoundland, Canada, and 3D Projects, Jamaica, West Indies.

Parving A (1984) Early Detection and Identification of Congenital/Early Acquired Hearing Disability. Who Takes the Initiative?. Int J Ped Otorhinolaryngology. 7: 107 -117.

Paul FM (1981) The problems of mental subnormality in a developing country. In : P Mittler (ed) Frontiers of knowledge in mental retardation. Baltimore: University Park Press.

Periquet A (1984) Community - based rehabilitation services: the experience of Bacolod, Phillipines and the Asia/Pacific Region. (Monograph No. 26). New York: World Rehabilitation Fund.

Pharoah POD, Connolly KJ, Ekins RP, Harding AG (1984) Maternal thyroid hormone levels in pregnancy and the subsequent cognitive and motor performance of the children. Clin Endocrinol (Oxf). 21: 265 - 270.

Pharoah P, McKinlay I (1986) The prevalence of neurological disability. Br Med Bull. 42 (2) : 139.

Phillips RE, Solomon T (1990) Cerebral malaria in children. Lancet. 336: 1355 - 1359.

Popham WJ (1978) Criterion-referenced Measurement. Englewood Cliffs, New Jersey: Prentice - Hall.

Rahman Omar M (1989) Country report on Bangladesh. Paper presented in the Health Information and Planning Workshop organised by the Dept. of International Health, Harvard University, and BRAC, June, 1989, Dhaka, Bangladesh.

Ramalingaswami V et al (1961) The aetiology of Himalayan endemic goitre. Lancet. 1: 791.

Rehabilitation International (1981) Annual Report, New York.

Reves R (1985) Declining fertility in England and Wales as a major cause of the Twentieth Century decline in mortality. Am J Epid. 122 (1) : 112.

Reynell J (1969) Reynell Developmental Language Scales. Windsor: NFER.

Richardson RA, Birch HG, Hertzig ME (1973) School performance of children who were severely malnourished in infancy. Am J Ment Def. 77: 623.

Richman N, Stevenson J, Graham P (1982) Preschool to school: a behavioural study. London: Academic Press.

Rogers P, Lydon P, Seckler D (1989) Eastern Waters Study : Strategies to manage flood and drought in the Ganges - Brahmaputra Basin. Irrigation Support Project for Asia and the Near East, USAID.

Rohde JE (1989) Health for all in China: principles and relevance for other countries. In: D Morley, JE Rohde, G Williams (ed). Practising health for all. Oxford University Press, Oxford.

Rose G, Becker DJP (1978) Epidemiology for the uninitiated: screening. Br Med J. ii: 1417 - 1418.

Rust J, Golombok S (1989) Modern Psychometrics. The science of psychological assessment. London: Routledge.

Rutter M, Martin JAM (1972) The Child with Delayed Speech. Clinics in Developmental Medicine, No. 43. London: SIMP with Heinemann Medical; Philadelphia: JB Lippincott.

Saksena DN, Srinivastava JN (1980) Biosocial correlates of perinatal mortality, experience of an Indian hospital. J Biosoc Sci. 12 : 69 - 81.

Scarr S (1981) Race, Social Class and Individual Differences in IQ. Lawrence Erlbaum, Hillsdale, New Jersey.

Schein JD, Delk MT Jr, (1974) The Deaf Population of the United States. Silver Spring, MD, National Association of the Deaf. p. 3 7.

Schlesselman JJ (1982) Case - control studies: design, conduct and analysis. New York: Oxford University Press.

Schmidt B, Kirpalani H, Rosenbaum P, Cadman D (1988) Strengths and limitations of the Apgar Score: a critical appraisal. J Clin Epidemiol. 41 (9): 843 - 850.

Schmutzhard E, Gerstenbrand F (1981) Cerebral Malaria in Tanzania: its epidemiology, clinical symptoms and neurological long - term sequelae in the light of 66 cases. Trans R Soc Trop Med Hyg. 78: 351 - 353.

Scrimshaw SCM, Hurtado E (1987) Rapid Assessment Procedures for Nutrition and Primary Health Care: Anthropological Approaches to improving programme effectiveness. UCLA Latin America Center Publications, University of California, Los Angeles.

Serpell R (1988) Childhood Disability in a Sociocultural Context: Assessment and Information Needs for Effective Services. In: PR Dasen, N Sartorius, JW Berry (eds) Health and Human Development: Applications from Cross-cultural Psychology. California: Sage.

Serpell R, Nabuzoka D (1991) Early intervention in third world countries. In: D Mitchell, RI Brown (eds) Family Intervention Studies for Young Children with Special Needs. London: Chapman and Hall.

Shorvon SD, Farmer PJ (1988) Epilepsy in developing countries: a review of epidemiologic, sociocultural, and treatment aspects. Epilepsia. 29 (suppl. 1): S36 - S54.

Shrout P, Newman S (1989) Design of two phase prevalence surveys of rare disorders. Biometrica. 45: 549 - 555.

Sisk C, Ziegler DK, Zileli T (1970) Discrepancies in recorded results from duplicate neurological history and examination in patients studied for prognosis in cerebrovascular disease. Stroke. 1: 14 - 18.

Slater A (1990) Infant Development: the Origins of Competence. The Psychologist: Bulletin of the British Psychological Society. 3: 109 - 113.

Soewarso TI (1978) Poliomyelitis in Indonesia. Epidemiological Bulletin: Second Quarter. 25 - 32.

Sommer A, Hussaini G, Tarwotjo I, Susanto D (1981) Incidence, prevalence and scale of blinding malnutrition. Lancet. i: 1407 - 1408.

Sommer A (1982) Field guide to the detection and control of xerophthalmia. WHO, Geneva.

Sonksen PM (1983) The assessment of 'vision for development' in severely visually handicapped babies. Acta Opthalmologica. Supplement 157 : 82 - 91.

Sonksen PM, Levitt S, Kitsinger M (1984) Identification of constraints acting on motor development in young visually disabled children and principles of remediation. Child: care, health and development. 10: 273 - 286.

Sonksen PM, Macrae AJ (1987) Vision for coloured pictures at different acuities: The Sonksen Picture Guide to Visual Function. Dev Med Child Neurol. 29 : 337 - 347.

Statham L, Murray MP (1971) Early walking patterns of normal children. Clin Orthop. 79 : 8 - 24.

Stein Z, Susser M (1980) The less developed world: Southeast Asia as a paradigm. In: J Wortis (ed) Mental Retardation and Developmental Disabilities: An Annual Review XI. New York: Brunner Mazel, p. 227.

Stein Z (1981) Why is it so important to measure incidence and prevalence?. Int J Ment Heath. 10 (1): 14 - 22.

Stein Z (1986) Severe mental retardation: epidemiology, causes and prevention. Paper I: prepared for the WHO sponsored visit to Nanjing, Poeple's Republic of China, May 5 - 15.

Stein Z, Belmont L, Durkin M (1986) Mild mental retardation and severe mental retardation compared: experiences in the eight less developed countries. Paper presented for the 2nd European Symposium on Scientific Studies in Mental Retardation, Uppsala, Sweden, June 24 - 26.

Stevenson J, Richman N (1978) Behaviour, language and development in three-year old children. J Aut Child Schizo. 8 : 299 - 313.

Stewart-Brown SL, Haslum MN (1988) Partial sight and blindness in children of the 1970 birth cohort at 10 years of age: J Epid Comm Health. 42: 17 - 23.

Stott DH, Moyes FA, Henderson SE (1972) A Test for Motor Impairment. London: National Foundation for Educational Research.

Susser M, Watson W, Hopper K (eds) Sociology in Medicine. 3rd edition. New York: Oxford University Press.

Sutherland DH (1984) Gait disorders in childhood and adolescence. Baltimore: Williams and Wilkins.

Sykes GS, Molloy PM, Johnson P, Gu W, Ashworth F, Stirrat GM, Turnbull AC (1982) Do Apgar Scores indicate asphyxia?. Lancet. i: 494 - 496.

Tarimo E, Creese A (eds) (1990) Acheiving Health for All by the Year 2000. Midway reports of country experiences. WHO, Geneva.

Taylor DC (1987) Epilepsy and Prejudice. Arch Dis Child. 62 : 209 211.

Thorburn M, Durkin M, Hasan M, Zaman S (1989) Low-cost methods for the rapid identification and assessment of childhood disability in Jamaica. Paper presented at the Caribbean Medical Research Committee Meeting.

Thorburn MJ (1990) Practical aspects of programme development (1) : prevention and early intervention at the community level (2): training, resource mobilisation, public education, and programme assessment. In: MJ Thorburn, K Marfo (eds) Practical Approaches to Childhood Disability in Developing Countries. Canada: project Seredec and Jamaica 3D Project.

Tielsch JM, Sommer A (1984) The Epidemiology of Vitamin A Deficiency and Xerophthalmia. Ann Rev Nutr. 4: 183 - 205.

Touwen BRL (1979) Examination of the child with minor neurological dysfunction. London: William Heinemann Medical Books.

Townsend JW, Klein RE, Irwin MH, Owens W, Yarborough C, Engle P (1982) Nutrition and preschool mental development. In: DA Wagner and HW Stevenson (eds) Cultural perspectives on child development. San Francisco : WH Freeman Company.

Tsou SCS, Gershon J, Simpson KL, Chichester CO (1984) Promoting household gardens for nutrition improvement. In: V Tanphaichitr, W Dahlan, V Suphakarn, A Valyasevi (eds) Human Nutrition: better nutrition better life. Proceedings of the fourth Asian Congress on Nutrition, Bangkok, Thailand, November 1983. Bangkok: Aksornsmai Press. 179 - 185.

Ulfah NM, Parastho S, Sadjimin T (1981) Polio and lameness in Yogyakarta, Indonesia. Int J Epid. 10 (2): 171 - 175.

Vernon M (1970) Clinical phenomenon of cerebral palsy and deafness. Except Child. 36 : 743 - 751.

Vijayaraghavan K, Radhaiah G, Surya Prakasam B, Rameshwas Sarma K, Vinodini Reddy (1990) Effect of massive dose Vitamin A on morbidity and mortality in Indian children. Lancet. 336: 1342 - 1345.

Wachs TD, Sheehan R (1986) Assessment of Young Developmentally Disabled Children. New York: Plenum Press. p.26.

Walsh JA, Warren KS (1979) Selected Primary Health Care. New England J Medicine. 301 : 967 - 974.

Walt G (ed) (1990) Community health workers in national programmes: just another pair of hands?. Milton Keynes: Open University Press.

Wedell K, Roberts (1982) Special education and research: a recent survey. Special Education: Forward Trends. 9 (3): 19 - 25.

Werner D (1986) Project Proximo. A village-run rehabilitation programme for disabled children in Mexico. Hesperian Foundation, Palo Alto, California.

Werner D (1987) Disabled Village Children. Palo Alto, CA, USA: The Hesperian Foundation.

Werner D (1989) Health care in Cuba: a model service or a means of social control or both?. In: D Morley, JE Rohde, G Willians (eds) Practising health for all. Oxford: Oxford University Press.

West KP, Sommer A (1987) Delivery of oral doses of Vitamin A to prevent Vitamin A deficiency and nutritional blindness. A state-of-the-art review. ACC/SCN state-of-the-art series. Nutrition policy discussion paper no.2.

WHO (1973) Organizational Study on Methods of Promoting the Development of Basic Health Services. Official records of the WHO, no. 26, Geneva.

WHO (1979a) Saving lives by immunization. WHO Chronicle. 33: 128 130.

WHO (1979b) Training and utilization of Auxilliary Personnel for Rural Health Teams in Developing Countries. Technical Report Series 633. WHO, Geneva.

WHO (1980a) Sixth report on the world health situation - Part One: Global Analysis. Geneva: World Health Organization.

WHO (1980b) International Classification of Impairments, Disabilities, and Handicaps. WHO: Geneva.

WHO (1980c) A manual for treatment of acute diarrhoea. Geneva: World Health Organization.

WHO (1982) Community-based rehabilitation. Report of a WHO Inter-regional Consultation, Columbo, Sri Lanka, 28 June - 3 July, 1982. Document RHB/IR/82.1, Geneva: World Health Organization.

WHO (1990) Programme for control of acute respiratory infections: Interim programme report. Geneva: World Health Organization.

Young A (1983) The relevance of traditional medical cultures to modern primary health care. Soc Sci and Med. 17 (16): 1205 - 1211.

Zaman S (1986) The Care and Education of Disabled Children in Bangladesh. In: K Marfo, S Walker, B Charles (eds) Childhood Disability in Developing Countries. New York: Praeger Publishers.

Zaman S, Khan Naila, Islam Shaheen, Dixit Shanta, Shrout Patrick, Durkin Maureen (1990) Validity of the 'Ten Questions' for screening serious childhood disability: Results from Urban Bangladesh. Int J Epid. 19 (3) : 613 - 620.

APPENDIX 1

PAGE 1 OF 4 File: REAHF

Household Form (HF) (April 1987 Revision)

Interviewer: Complete one HF for every household in the area with at least one 2 to 9 year-old child.

Household Number: ☐ | ☐ | ☐☐☐☐ HF1
Area Site House Number

Head of Household's Full Name: _____

Address or Village: _____

What kind of work does (or did, if retired) the head of the household mainly do? ☐ HF2

Use locally relevant categories, for example:

1. agricultural
2. fishing
3. unskilled labor
4. business/sales
5. clerical/service
6. skilled/professional work
7. mainly unemployed
8. other, specify _____
9. no information

	Interviewer Visits 1	2	3	Final Visit	
Date (day/month/year):	__/__/__	__/__/__	__/__/__	☐☐|☐☐|☐☐	HF3
Interviewer's Number:	__ __	__ __	__ __	☐☐	HF4
Result 1. completed	___	___	___	☐	HF5

2. not home
3. postponed
4. refused
5. partly completed
6. other (explain)

Interviewer: If the interview is refused or not completed for another reason, please complete the Refusal Information on page 4 (reverse side of page 3) of this form.

	Field Edited By	Office Edited By	Keyed By
Name	_____	_____	_____
Date	_____	_____	_____

Household Number: __|__|_____
Area Site House Number

Interviewer: Codes "9" and "99" generally indicate "no information."
Use these codes only after probing to try to get the correct information.

Which category best describes the ethnicity and/or religion of members of the household? ☐ HF6

(Codes to be devised for locally relevant categories.)

Does the head of this household own this house or rent it? ☐ HF7
1. owns the house 2. rents the house

How many rooms are there in your house? ☐☐ HF8

Does your house have:
Electricity? YES ☐ NO ☐ HF9
A Radio? YES ☐ NO ☐ HF10
A Television? YES ☐ NO ☐ HF11

Does any member of your household own:
A Bicycle? YES ☐ NO ☐ HF12
A Motorcycle? YES ☐ NO ☐ HF13
A Car or Jeep? YES ☐ NO ☐ HF14
A Boat? YES ☐ NO ☐ HF15
Some Land? YES ☐ NO ☐ HF16

What is the main material of the floor of your house? ☐ HF17
1. earth/sand 2. cement
3. wood 4. other (specify)

What is the major source of drinking water for members of your household? ☐ HF18
1. piped into house 2. piped into yard or plot 3. public tap
4. well 5. river, spring, surface water 6. vendor (eg, tanker truck)
7. rainwater 8. other (specify)

What is the major source of water for household use other than drinking? ☐ HF19
1. piped into house 2. piped into yard or plot 3. public tap
4. well 5. river, spring, surface water 6. vendor (eg, tanker truck)
7. rainwater 8. other (specify _____)

What kind of toilet facility does your household have? ☐ HF20
1. flush 2. bucket 3. pit
4. other (specify _____) 5. none

Household Number: __|__|_____
Area Site House Number

How many people 10 years and older usually live in your household? ☐☐ HF21

How many children 9 years and younger usually live in your household? ☐☐ HF22

Are there any other persons living here that were not counted above?

If yes, enter number of additional persons 10 years and older: ☐☐ HF23

additional persons 9 years and younger: ☐☐ HF24

How many mothers are living in this house with children aged 2 to 9 years? ☐ HF25

Are there any 2 to 9 year-old children living here without their mothers?

YES ☐ NO ☐ HF26

Interviewer: If yes, find out how many mothers not living here (whether alive or dead) have 2 to 9 year-old children who do live here and enter the number of such mothers: ☐ HF27

Total number of Mother-Child Forms needed for this household: ☐ HF28

(HF28 should be equal to HF25 plus HF27)

Interviewer: After finishing this household form, complete one Mother-Child Form for each mother who has 2 to 9 year-old children (or child) residing in the household. If the mother is not alive, is living elsewhere or is not available for interview for another reason, try to get the information from someone who knows about her.

APPENDIX 2

 File: REAMC

Mother-Child Form (MCF)

(May 1987 Version, Bangladesh & Pakistan)

ONE FORM TO BE FILLED OUT FOR EACH SET OF CHILDREN IN THE HOUSEHOLD WHO HAVE THE SAME MOTHER.

Household Number: ☐ | ☐ | ☐☐☐☐ (Area | Site | House) HH1

Mother Number: ☐ MC1

Interviewer's Number: ☐☐ MC2

Head of Household's Full Name: _____

Relationship of mother to head of the household: ☐ MC3

1. self 2. wife 3. mother
4. daughter or granddaughter 5. daughter-in-law 6. other relative
7. servant 8. other nonrelative

Relationship of informant to mother: ☐ MC4

1. self 2. father of the child/children
3. parent of the mother (grandparent of the child/children)
4. other relative of the mother 5. other (specify)

In what month and year were you (the mother) born? ☐☐/☐☐ MC5
(don't know=98/98) Month Year

How old were you (the mother) at your last birthday? (don't know=98) ☐☐ MC6

What was the highest level of school you (the mother) attended? ☐ MC7

1. never attended school 2. primary 3. secondary 4. higher

Can you (the mother) read a letter or newspaper easily, with difficulty, or not at all? ☐ MC8

1. easily, 2. with difficulty, 3. not at all

Do you (the mother) now work outside the home? YES ☐ NO ☐ MC9

If yes, ask:

What kind of work do you (the mother) mainly do? ☐ MC10

Use locally relevant categories, for example:

1. agricultural 2. fishing 3. unskilled labor
4. business/sales 5. clerical/service 6. skilled/professional work
7. other 8. not applicable 9. no information

Do you (the mother) earn wages for your work? YES ☐ NO ☐ MC11

Were you and your husband (the child's mother and father) related to each other (for example, as cousins or as uncle and niece) before marriage? YES ☐ NO ☐ MC12

__ | __ | __ __ __ __ | __
Area Site House Mother

BIRTH HISTORY:

Note: The questions below concern live births only.
Do not record miscarriages, abortions or stillbirths.

How many times have you (the mother) given birth to a live baby? ☐☐ MC13

Have any of your (the mother's) babies or children died? YES ☐ NO ☐ MC14

If yes, enter number: ☐☐ MC15

How many of your children are now living? ☐☐ MC16

Note: MC16 should equal MC13 minus MC15. If not, ask again and make corrections.

Interviewer: Say to the respondent: "Now I would like to talk to you about your (the mother's) births, starting with the first one you (the mother) had, and including all, whether still alive or not." First complete column 1 by asking her to list the name of each child, beginning with the first born and ending with the last born. Then go back and ask the sex, birthday and other information for each child, and record the information.

What name was given to your (first, next) baby?	Is (NAME) a boy or girl? (circle one)	In what month & year was NAME born?	Is (NAME) still alive? (circle one)	If dead, how old was (NAME) when he/she died? RECORD DAYS IF <1 mo., MONTHS IF <2 YEARS, OR YEARS	If alive, how old was (NAME) at his/her last birthday? RECORD AGE IN COMPLETED YEARS	If alive, is he/she living in this house? (circle one)	Child Number
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: ☐☐ months: ☐☐ years: ☐☐	age: __ __	yes no	01
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: ☐☐ months: ☐☐ years: ☐☐	age: __ __	yes no	02
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: ☐☐ months: ☐☐ years: ☐☐	age: __ __	yes no	03
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: ☐☐ months: ☐☐ years: ☐☐	age: __ __	yes no	04
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: ☐☐ months: ☐☐ years: ☐☐	age: __ __	yes no	05

Area Site House Mother

_____	boy girl	__ __/__ __ mo. yr.	yes no	days: □□ months: □□ years: □□	age: __ __	yes no	06
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: □□ months: □□ years: □□	age: __ __	yes no	07
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: □□ months: □□ years: □□	age: __ __	yes no	08
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: □□ months: □□ years: □□	age: __ __	yes no	09
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: □□ months: □□ years: □□	age: __ __	yes no	10
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: □□ months: □□ years: □□	age: __ __	yes no	11
_____	boy girl	__ __/__ __ mo. yr.	yes no	days: □□ months: □□ years: □□	age: __ __	yes no	12

Interviewer: Circle the child number of each 2 to 9 year-old child listed above who is still living and lives in this house. Then complete one Ten Questions with Probes Form (TQ) for each child whose number is circled. Use the child numbers assigned above on the child's TQ form.

Use additional sheets if one mother had more than 12 live births.

Enter the number of TQ forms to be completed for children listed on this form: □ MC17

APPENDIX 3

Ten Questions with Probes, and the Rules for Scoring

Question 1: Comapred to other children, did the child have any serious delay in sitting, standing or walking?
Probe: DID THE CHILD WALK BY THE AGE OF 2 YEARS?

The probe question in this case tries to distinguish the child with serious delay in milestones from one who might have had some delay in attaining milestones, but who was well within the norm. Thus to be considered a positive on the TQP with probes for this question, a positive response on the main question will have to be followed by a negative response on the probe question.

Question 2: Compared with other children, does the child have any difficulty seeing, either in the daytime or at night?
Probe 1: IS THE DIFFICULTY ONLY AT NIGHT?
Probe 2: CAN HE SEE THAT? (POINT TO A SMALL OBJECT IN THE HOME)
Probe 3: DOES HE/SHE HAVE SOME OTHER EYE PROBLEM?
If yes to this probe, write down what the parent says.

This first probe identifies children with nutritional blindness. If this probe is answered in the negative, then the child could either have other vision problems or be a false positive on vision. Thus, for the present analysis, this probe will be ignored, and the probe on night-blindness will be assessed separately. A child will be considered positive on the vision given a negative response to the second probe question. In the case of the third probe question, the child will be considered positive only if the example given indicates a vision problem.

Question 3: Does the child appear to have difficulty hearing?
Probe 1: CAN THE CHILD HEAR AT ALL?
Probe 2: DOES THE CHILD HAVE ANY OTHER PROBLEM WITH HIS/HER EARS?
If yes, write down what the parent says.

A child will be considered positive on hearing if the first probe is answered in the negative, or if the example given in connection with the second probe signifies a vision problem.

Question 4: When you tell the child to do something, does he/she understand what you are saying?
Probe: IF YOU ASK HIM/HER TO BRING YOU A CUP (BUT YOU DO NOT POINT), IS HE/SHE ABLE TO DO IT?

This probe differentiates a child that may have difficulties carrying out sophisticated tasks from one that is unable to follow basic instructions. If the probe is answered in the negative, then the child will be considered positive on this question.

Question 5: Does the child have difficulty walking or moving his/her arms or does he /she have weakness or stiffness in the arms or legs?
Probe 1: DOES HE/SHE NEED HELP IN WALKING?
Probe 2: CAN HE/SHE USE HIS/HER ARMS TO PICK UP THINGS?
Probe 3: DOES HE/SHE HAVE STIFFNESS?
Probe 4: DOES HE/SHE HAVE WEAKNESS?

For the purpose of this dissertation, the last two probes have not been used. The child is considered to be positive on the probe for movement if he/she either needs help walking or cannot use arms to pick up things.

Question 6: Does the child sometimes have fits, become rigid or lose consciousness?
Probe 1: HAS HE/SHE HAD A FIT IN THE LAST YEAR?
Probe 2: DO THE FITS INTERFERE WITH HIS/HER USUAL ACTIVITIES (LIKE DOING CHORES OR GOING TO SCHOOL, IF OLD ENOUGH)?

Recency of fit is considered to be a strong risk factor for another fit, and diagnosis of epilepsy. If the first probe is answered positive, then the child is at risk of being epileptic. If fits interfere with activities, then by definition, they are severe and disabling. If the child has had either a recent or a disabling fit in the past, he/she will be considered positive for the seizure question on the TQP.

Question 7: Does the child learn to do things like other children his/her age?
Probe 1: CAN YOU TELL ME SOMETHING THAT HE/SHE SEEMED TO HAVE DIFFICULTY LEARNING?
Probe 2: DOES THE INFORMANT GIVE AN EXAMPLE?
If yes, write down the example.

The first probe gives an opportunity to the informant to specify the specific area of cognitive deficit of the child. The example provided on this occasion should help to determine whether or not the child does have a problem. Thus, if the first probe is answered in the affirmative, but the example given does not indicate a problem, then the child will be considered negative for this question.

One point to bear in mind here is that whether or not these probes are answered may reflect the informant's ability to provide specific information rather than the specific cognitive deficit of the child.

Question 8: Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognisable words)?

This question has no probes. It is assumed that if the child is positive on this question, he/she is unable to speak, and thus is disabled. Question Nine is to be redundant for children who cannot speak.

Question 9: (3-9 years) Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?
Probe 1: DOES HE/SHE STAMMER OR STUTTER?
Probe 2: DOES HE/SHE HAVE SOME OTHER PROBLEM WITH HIS/HER SPEECH?
If yes to this probe, write down what the parent says.

A child who only stammers or stutters will not be considered to have a speech problem. Thus only a child that has a positive entry in the second probe and where the example given indicates a speech problem will be considered positive on the TQP for speech.

Question 9: (2 years) Can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?
Probe: DID HE/SHE USE HIS/HER OWN WORDS FOR THINGS, LIKE BOW-WOW FOR DOGS?

A normal 2-year-old is expected to have a few words of his/her own. Thus if by 2 years the child does not have a few words, he/she will be considered positive for speech on the TQP.

Question 10: Compared with other children of his/her age, does the child appear in any way to be mentally backward, dull or slow?
Probe: WOULD YOU SAY THAT HE/SHE IS MUCH BEHIND OTHER CHILDREN OF HIS/HER AGE, THAT HE/SHE ACTS LIKE A MUCH YOUNGER CHILD?

To be TQP positive on this question, the probe question has to be entered in the affirmative.

APPENDIX 4

File: REAMAF1

MEDICAL ASSESSMENT Form (MAF)

(August 1987 Revision)

Household Number: ___ | ___ | ___ ___ ___ ___ HF1
Area Site House

Mother Number: ___ MC1

Child Number: ___ ___ TQ1

Examiner Number: ___ ___ M1

Child's Name: _____

Head of Household's Name: _____

Child's Month and Year of Birth (month/year; if not known do not estimate, enter 98/98): ___ ___ ___ ___ M2

Child's Age (in completed years: estimate if not known): ..... ___ M3

Child's Sex: Boy =1 Girl=2 ..... ___ M4

Who will answer the questions about the child? ..... ___ M5
the child's mother =1 the child's grandmother=3 another relative =5
the child's father =2 the child's sibling =4 other =6

Contents of the Medical Assessment Form — Pages

Instructions:

Part I. **History.** Administer as a semi-structured interview. Ask all the questions specified in this form. Use local terminology if necessary to insure that the informant understands the questions. After each question you may probe for additional information and use your clinical judgement to arrive at the answer. (For example, if a mother reports fits, but on questioning it appears the child fainted without ever actually having a seizure, do not code epilepsy.) Be sure to answer all questions. Most should be answered by writing the code in the space provided. Some of the questions require a brief answer in words.

Parts II, III, and IV. **The Examination.** Note special instructions on page 9 for the functional observation of the child. You may vary the order in which you carry out the various parts of the examination, except that the observation of function must come before the neurological (because only the children with problems noticed on the observation of function, are given the full neurological, page 13). All children receive all the other parts of the examination.

Part V. The **physical measurements** and **hearing and vision screening** may be performed by either a doctor or by another health worker.

Part VI. The **Summary Sheet** must be filled out by the doctor after completing the assessment.

See Medical Assessment Procedure Manual for further instructions.

Prepared by: Leslie Davidson (USA) and Naila Khan (Bangladesh), Marigold Thorburn (Jamaica), Zaki Hasan (Pakistan), and Maureen Durkin (USA), with help from Zena Stein, Lillian Belmont and other colleagues in the Sergievsky Center and Judy Gravel, Victoria Sheffield and Karin Nelson.

For the projects: Rapid Epidemiologic Assessment of Childhood Disabilities in Bangladesh, Jamaica and Pakistan.

Child's ID: __|__|_____|__|__

I. History

A. PERCEIVED PROBLEMS. Ask the parent:

IS THERE ANYTHING ABOUT YOUR CHILD THAT WORRIES YOU?

Examiner: If yes, inquire about the problems and complete the table below. After recording the information for one problem area, ask about all other problem areas and complete the table. When no problem is perceived in an area, circle No and leave the remaining boxes blank for that area.

If no to the first inquiry, still ask specifically about each problem area and complete the table.

When more than one option in the table seems to apply, enter the main one in the box and write the codes for others in [ ] to the right of the box. In the box for family history, enter the smallest number that applies.

PROBLEM AREA	Does the parent perceive a problem? (circle No or Yes)	APPROXIMATE AGE AT ONSET IN MONTHS: at birth =888, d/k =998, (eg, at 1 mo=001) (estimate if exact age of onset is not known)	EVENT ASSOCIATED: none =1, prenatal =2, birth trauma =3, fever,infection =4, injury =5, malnutrition =6, other(specify) =7	TREATMENT RECEIVED: none =1, modern only =2, folk only =3, both =4, d/k =8	FAMILY HISTORY: none =1, parent =2, sibling =3, grandparent =4, 1st cousin,aunt,uncle =5, other blood relative =6, d/k =8
Walking:	No Yes	☐☐☐	☐	☐	☐
If yes, describe:	m6	m14	m21	m28	m35
Using Hands:	No Yes	☐☐☐	☐	☐	☐
If yes, describe:	m7	m15	m22	m29	m36
Hearing:	No Yes	☐☐☐	☐	☐	☐
If yes, describe:	m8	m16	m23	m30	m37
Vision:	No Yes	☐☐☐	☐	☐	☐
If yes, describe:	m9	m17	m24	m31	m38
Speech:	No Yes	☐☐☐	☐	☐	☐
If yes, describe:	m10	m18	m25	m32	m39
Seizures:	No Yes	☐☐☐	☐	☐	☐
If yes, describe:	m11	m19	m26	m33	m40
Learning:	No Yes	☐☐☐	☐	☐	☐
If yes, describe:	m12	m20	m27	m34	m41
Other:	No Yes				
If yes, describe:	m13				

Additional Comments:

Child's ID: __|__|__ __ __ __|__|__ __

B. FAMILY: Are the parents of the child related to each other? ..... ___ m42
no =1 yes, as first cousins=3 yes, as distant cousins=5
yes, as uncle and niece=2 yes, as second cousins=4 unknown=8

C. SEIZURES: Ask these questions whether or not the mother said her child has seizures on page 1. Probe to find out the frequency of seizures, if these are associated conditions and find out the setting in which they occurred. Codes for questions 1 through 4 below: no=1 yes =2 unknown=8

1. Did (does) the child have febrile fits (fits with fever)? ..... ___ m43
2. Did the child have other provoked fits (fits with dehydration, shigella, meningitis, toxins, trauma (within 24 hours of trauma))? ..... ___ m44
3. Did the child have breath holding spells (loss of consciousness, in setting of anger, pain frustration, or crying)? ..... ___ m45
4. Has the child ever had unprovoked afebrile seizures? ..... ___ m46

If yes, please describe _____
If no, skip to section D.

5. If the child has had unprovoked afebrile seizures, how frequent and how current are they? never =1 only 1 ever=2 >1 total but none in past 12 mos =3 >1 total & ≥1 in past 12 mos=4 unknown=8 ..... ___ m47

6. Does the child get medication for seizures?

Code medications: no=1 yes=2 unknown=8

If yes to any, explain _____

Phenobarbital	___	m48
Dilantin	___	m49
Other Western	___	m50
Traditional / Herbal	___	m51

D. PREGNANCY (for birth of this child): Enter the correct numbers for gravidity, parity, stillbirths and spontaneous abortions that applied at the time of this child's birth. Gravity is defined as the total number of pregnancies before this child (and counting this child). Parity is defined as the total number of actual births before this child (and counting this child).

Gravidity	___ ___	m52
Parity	___ ___	m53
Stillbirths	___	m54
Spontaneous Abortions	___	m55

When the mother was pregnant with this child did she have:
Code: no=1 yes =2 unknown=8

High Blood Pressure?	___	m56
Bleeding 1st trimester?	___	m57
Infection/Fever 1st trimenster?	___	m58
*Other Health Problems?	___	m59
Did she have antenatal care?	___	m60
Has she ever had a goiter?	___	m61

*Do not include here problems with veins, pyelonephritis, moderate vomiting or mild conditions.

E. BIRTH:

Where was the child born? Home=1 Hospital =2 Clinic/Birthing Center=3 Other=4 Unknown=8 m62

Was it a single birth? Single birth=1 Twins =2 Triplets or more=3 Unknown=8 ..... m63

Was the baby born at 9 months? Yes=1 No, >1 mo.early=2 No, >2 weeks late=3 Unknown=8 ..... __ m64

Child's ID: __|__|_____|__|__

BIRTH continued:

How long was the labor? <24 hours=1 ≥24 hours=2 Unknown=8 ___ m65

Who assisted in delivering the baby? Trained midwife/TBA=1 Doctor=3 Other =5 ___ m66
Untrained TBA/dai=2 Family member=4 Unknown=8

Were there any difficulties at birth? No=1 Yes=2 Unknown=8 ___ m67
If yes, explain: _____

In what position did the baby come out? Head first=1 Foot first=3 Unknown=8 ___ m68
Bottom first=2 Cesarian=4

Did the baby cry immediately? Yes=1 No, after >5 minutes=3 ..... ___ m69
No, but in ≤5 min.=2 Unknown=8

Did the birth attendant have to do anything to the baby to make it breathe? ..... ___ m70
If yes, why _____ No=1 Yes=2 Unknown=8

Was the baby taken away from the mother? No=1 Yes=2 Unknown=8 ..... ___ m71
If yes, why _____

If the baby was kept in a hospital, for how many days was it kept there? ..... ___ ___ m72

What was the birthweight in grams? 9999=Unknown ___ ___ ___ ___ m73
(If given in pounds, write ____lbs. and ____oz. here _____, then convert to grams.)

How big was the baby at birth? About the size of most babies=1 Bigger than most babies=3 ___ m74
Smaller than most babies=2 Unknown =8

Did the child have any difficulties in the first four weeks?
Code: No =1
Yes =2
Unknown =8

Seizures ___ m75
Infection ___ m76
Trouble Feeding ___ m77
Yellow Color ___ m78
Tetany ___ m79
Diarrhea ___ m80
Difficulty Breathing ___ m81

F. NUTRITIONAL HISTORY:

Was the child breast-fed & for how long? No, never=1 Yes, 7 - 12 mo.=4 Yes, >24 mo.=7 ___ m82
Yes, <1 mo.=2 Yes, 13 - 18 mo.=5 Unknown=8
Yes, 1 - 6 mo.=3 Yes, 19 - 24 mo.=6

When did the child start bottle feeding? Never=1 7- 12 mo.=4 After 24 mo.=7 ___ m83
Within 1st mo.=2 13 - 18 mo.=5 Unknown=8
1 - 6 mo. =3 19 - 24 mo.=6

At what age was solid food introduced? 3 - 6 mo.=1 After 12 mo.=3 Unknown=8 ___ m84
7 - 12 mo.=2 Not yet=4

Can the child feed himself or herself? (assess in accordance with local cultural norms). ___ m85
Yes, skillfully (with spoon/fork or fingers)=1 Yes, but unskilled (i.e., like a baby)=2 No, must be fed=3

Child's ID: __|__|_____|__|___

G. DEVELOPMENTAL HISTORY:

At what age did the child walk without help or holding on? ____ m86
(Note: Codes 4 and 5 do not apply to children under 3 years.)
By 18 mo.=1 By 2 years=2 Btw 2 &3 years =3 By 3 years=4 Later than 3 years=5 Not yet=6 Unknown=8

At what age did the child first use single words with meaning (other than names, hello or bye-bye)? ____ m87
(Note: Codes 4 and 5 do not apply to children under 3 years.)
By 18 mo.=1 By 2 years=2 Btw 2 &3 years=3 By 3 years=4 Later than 3 years=5 Not yet=6 Unknown=8

At what age did the child first put two or three words together? ____ m88
(Note: Codes 3 and 4 do not apply to children under 3 years.)
By 2 years=1 Btw 2 &3 years=2 By 3 years=3 Later than 3 years=4 Not yet=5 Unknown=8

H. MEDICAL HISTORY:

Note: Use local expressions when discussing with the informant the diseases and medical problems mentioned in this form.

IMMUNIZATIONS: Refer to the child's immunization record if the mother brings is with her.

Has the child ever been immunized for:.....

Code: yes, complete=1; yes, but incomplete=2; no=3; unknown=8

Polio ____ m89

Whooping Cough, Diphtheria (DPT) ____ m90

Tetanus Toxoid ____ m91

TB (BCG) ____ m92

Ask the following question even if information on specific immunizations is recorded above.

Has the child had any immunizations? Yes=1 No=2 Unknown=8 ____ m93

Explain _____

Note: If the mother answers yes to any of the medical problems mentioned in the next few pages, inquire specifically if the event was the cause of any of the problems described by the mother in the beginning of the interview. If so, write it in this section and also on page 2 in the column called "Event Associated."

Note: For the remaining questions on medical history: If the answer is yes, enter the approximate age of the child in months when the event occurred. If the event occurred in the perinatal period, enter 001 for age. If approximate age is not known enter 998 for age. If the answer to the question is not yes, leave the spaces for age blank. AGE IN MONTHS

Has the child ever had a bad infection in the brain, meningitis or encephalitis? ____ m94 ____ ____ m95 ____
No=1 Yes=2 Unknown=8
If yes, describe: _____ « mm1brain

Has the child ever had a major injury, such as the following? (read all choices):
If no, enter 1 and leave age blank
If yes, indicate type of treatment and age.

Codes: No=1; In hospital=2; Outpatient=3; Home care=4; Unknown=8

Motor Vehicle Accident ____ m96 ____ ____ m97 ____

Other Vehicle Accident ____ m98 ____ ____ m99 ____

Near Drowning ____ m100 ____ ____ m101 ____

Fall (1 level to another) ____ m102 ____ ____ m103 ____

Burns (not minor) ____ m104 ____ ____ m105 ____

Other ____ m106 ____ ____ m107 ____

If yes to any, describe: _____ « mm2injur

Child's ID: ☐☐ HF1 ☐☐☐☐☐ MC1 ☐ TO1 ☐☐

H. MEDICAL HISTORY continued:

Has the child ever lost consciousness after an injury to the head? m108 m109
No, never=1 Yes, <1 week=3 Yes, >1 month =5
Yes, <10 minutes=2 Yes, <1 month=4 Unknown=8

If yes, describe: _____ « mm3head

Has the child ever been poisoned by chemicals or cleaners or medicine? m110 m111
No, never=1 Yes, hospitalized=3
Yes, not hospitalized=2 Unknown=8

If yes, describe: _____ « mm4pois

Has this child had tuberculosis? No=1 Yes =2 Unknown=8 m112 m113

If yes, has he/she received treatment for tuberculosis? No=1 Yes=2 Unknown=8 m114 m115

Has this child had the measles? No=1 Yes mild=2 Yes severe=3 Unknown=8 m116 m117

If yes, describe _____

Has this child had whooping cough? No=1 Yes mild=2 Yes severe=3 Unknown=8 m118 m119

If yes, describe _____

Has the child ever been hospitalized? (at least overnight, other than at birth) m120 m121
No=1 Yes, once=2 Yes, >once=3 Unknown=8

If yes, enter age last hospitalized and describe _____

Has your child ever been very ill with diarrhea, vomiting and dehydration? m122 m123
No=1 Yes=2 Unknown=8

If yes, describe treatment _____

Has the child ever had any other major illness not mentioned so far? m124 m125
No=1 Yes=2 Unknown=8

If yes, describe _____

I. BEHAVIOR:

Does your child have any problems with behavior?

Code: No=1, Yes=2, Unknown=8

Does he/she:

Act very aggressively toward other people? ___ m126

Act extremely withdrawn and shy? ___ m127

Show odd repetitive movements? ___ m128

Other? ___ m129

If other, list problems: _____

_____

_____

_____

Physician: In your opinion, was the informant able to give an accurate history of the child? ___ m130
Yes=1 No, did not know child well=2 No, appeared muddled=3 Interviewer unsure=8

Additional Comments on History:

Child's ID: __|__|_____|__|___

II. **OBSERVATION OF FUNCTION:** COMPLETE FOR ALL CHILDREN.

Instructions: **Observe** the child carry out the 7 tasks listed below.

As the child and informant come into the room:

1. Observe the child walking at least 5 steps into room. Watch carefully, looking for limp asymmetry of gait, toe walking, ataxia, involuntary movements, and atrophy or contractures.

2. Welcome the child and observe the response; does he or she hear, make an appropriate social response, smile, act shy, speak?

3. Invite the child to squat and to pick up a tiny object, such as a bead, coin or raisin (defined size), using each hand in turn. Observe carefully for fisting, asymmetry in grasp, absence of pincer grasp, or difficulty in seeing the object.

4. Observe the child as he/she stands up: Does he/she need to use hands to get to an upright position? (proximal muscle weakness).

5. Elicit speech by asking the child questions such as: "What did you pick up?" "What is that?" (point to a raisin, chair, etc.) "What is this called?" (point to nose, ear, foot, etc.). "What is your name?" Watch for problems in hearing, speech and comprehension.

6. Ask the child to point to body parts (eyes, mouth, etc.). Observe for problems in hearing and comprehension.

7. Give the child paper and a pencil and ask him/her to draw something. Scribble (for 2 year old) or draw shapes: circle (for 3 year old), square (for 4 through 6 year old), diamond (for 7 through 9 year old). Observe fine motor function and comprehension.

Rate the child in the following areas after observing the above 7 tasks:

Code: **Pass=1**, Fail=2, Uncertain=3, No response=9

Gross Motor	___	m131
Fine Motor	___	m132
Hearing	___	m133
Vision	___	m134
Speech (Motor)	___	m135
Speech (Language)	___	m136
Comprehension	___	m137

Then have the child undress for the rest of the examination.
Complete the physical examination (pages 10 - 13) for all children.
Some children must have the neurological examination in addition to the physical.
Use the criteria outlined below to determine whether or not to complete the neurological exam for this child.

CRITERIA FOR DETERMINING WHICH CHILDREN MUST HAVE THE NEUROLOGICAL EXAM:

Give the neurological exam if:

1. The child fails or scores "uncertain" in any of the 7 areas rated above, or
2. Any of the following are true:
   a. the informant mentions that the child has had any neurological, sensory or cognitive problems.
   b. the physician notes microcephaly, macrocephaly or any atrophy on the physical exam.
   c. the physician suspects hearing or vision impairment.

Physician: Do you think, based on the interview with the informant and this brief observation that the child has a neuromuscular, vision, hearing or cognitive impairment? ___ m138

No=1 Yes=2 Uncertain=8

PLEASE DO NOT CHANGE YOUR ANSWER TO THIS LAST QUESTION AFTER COMPLETING THE REST OF THE EXAMINATION.

Additional Comments on the Observation of Function:

Child's ID: __|__|_____|__|__

III. PHYSICAL EXAMINATION: COMPLETE FOR ALL CHILDREN

A. Rate the child's general appearance as: ..... ___ m139

Overnourished =1 | No subcutaneous fat =3 | No fat and edematous=5
Well-nourished=2 | Diminished muscle mass =4 | Uncertain=8

B. Rate the presence of the following conditions:

Codes: No=1 Yes=2 Uncertain=8

HAIR:	Brittle/Discolored	___	m140
	Sparse	___	m141
SKIN:	Scars (Burns)	___	m142
	Weeping Sores	___	m143
	Ulcers	___	m144
	Cheilosis	___	m145
HEAD:	Microcephaly	___	m146
	Macrocephaly	___	m147
FACE:	Hypertelorism	___	m148
	Epicanthal folds	___	m149
	Flat Midface	___	m150
	Micrognathus	___	m151
	Facial Weakness	___	m152
EYES:	Ptosis	___	m153
	Brushfield Spots	___	m154
	Cataract	___	m155
	Retinitis	___	m156
	Trachoma	___	m157
	Squint	___	m158
	Conjunctivitis	___	m159
	Onchocerciasis	___	m160
	Nystagmus	___	m161
	Discs Pale/atrophic	___	m162
Xerophthalmia (see codes at left)	Right Eye	___	m163
	Left Eye	___	m164
EARS: Pneumatoscopy	Right Ear	___	m165
Code: Normal=1, Abnormal=2, Not Seen=8	Left Ear	___	m166
Otoscopy	Suppurative (Draining)	___	m167
Codes: No=1, Yes=2, Uncertain=8	Perforated	___	m168
	Inflamed : Acute Otitis	___	m169
	Fluid : Serous Otitis	___	m170
	Low Set or Deformed	___	m171
MOUTH:	Cleft Palate	___	m172
	Diminishing Gag	___	m173
	Missing Many Teeth	___	m174
	Many Carious Teeth	___	m175
	Drooling	___	m176
THYROID: « Enter WHO Goitre Classification		___	m177

Xerophthalmia Codes (ICD-9 and WHO)
Normal=1
Night Blindness=2
Conjunctival Xerosis=3
Bitot's Spot=4
Corneal Xerosis=5
Keratomalacia,1/3 corn.surf.=6
Keratomalacia/Corneal Ulcer>1/3 corn.surf.=7
Corneal Scars=8
N/A or missing data=9

THYROID: WHO Goitre Classification Codes:

- Thyroid not palpable or, if palable, not larger than normal. ..... =1
- Thyroid distinctly palpable and definitely larger than normal but usually not visible when head is in normal or extended position. =2
- Thyroid easily palpable and visible when head is in extended position. Presence of a discrete nodule also qualifies one for inclusion in this grade. ..... =3
- Thyroid easily visible with the head in a normal position. ..... =4
- Goiter visible at a distance..... =5
- Monstrous goiter. ..... =6
- Unknown. ..... =8

Child's ID: __|__|_____|__|___

PHYSICAL EXAMINATION continued:

Codes: No=1, Yes=2, Uncertain=8

CHEST:
- Rales ___ m178
- Wheezy ___ m179

COR:
- Murmur ___ m180

ABDOMEN:
- Distended ___ m181
- Hepatomegaly ___ m182
- Splenomegaly ___ m183

GENITALIA: (Code 1 for girls)
- Large Testes ___ m184
- Undescended Testicles ___ m185

SPINE:
- Kyphosis ___ m186
- Scoliosis ___ m187
- Spina bifida ___ m188

EXTREMITIES: (Arms, Legs and Feet)

Code: All Normal=1, Right Arm=2, Left Arm=3, Both Arms=4, Right Leg/Foot=5, Left Leg/Foot=6, Both Legs/Feet=7, One Arm & One Leg/Foot=8, Both Arms & Legs/Feet=9

- Wasting ___ m189
- Abnormal Angulation ___ m190
- Contractures ___ m191
- Absent ___ m192
- Atrophy ___ m193

HANDS:

Code: Both Normal=1, Right Hand=2, Left Hand=3, Both Hands=4

- Absent ___ m194
- Partial Absence ___ m195
- Digits Extra (Abnormal) ___ m196
- Short Fingers ___ m197
- Fisting ___ m198

Physician: In your opinion, did this constitute an adequate physical exam of the child? ___ m199
Yes=1 No, child uncooperative=2 3=No, not enough time=3 Not sure=8

Does this child get a full neurological examination based on results from Observation of Function, Physican Examination, or History? ___ m200
No=1 Yes=2

Additional Comments on the Physical Exam:

Child's ID: __|__|_____|__|___

IV. NEUROLOGICAL EXAM: FOR ALL CHILDREN WHO FAIL OR SCORE UNCERTAIN ON THE OBSERVATION OF FUNCTION.

MOTOR EXAM:

Mobility:

Normal Gait = 1
Not normal, but ambulant, no aids, independent = 2
Ambulant with aids, independent = 3
Ambulant with aids, limited = 4
Not ambulant, wheelchair only, but independent = 5
Not ambulant, wheelchair only, limited = 6
Not ambulant, bed ridden or wheelchair = 7
Uncertain = 8

____ m201

Manual Dexterity: (Observed during the Observation of Function)

Normal = 1 Marked Impairment = 4
Slight Impairment = 2 No useful function = 5
Moderate Impariment = 3 Unknown = 8

Right Hand: ____ m202

Left Hand: ____ m203

Use codes No = 1 Yes = 2 Uncertain=8 for the remaining questions in Part IV (unless otherwise indicated):

Is the child in a frogged position when lying down? ..... ____ m204

When you pick the child up under the arms do his/her legs scissor? ..... ____ m205
Code = 7 if child is too heavy to lift.

Move each of the four limbs around the major joints (shoulders, elbows, wrists, hips, knees and ankles)

Is any limb hypotonic?
Right Arm ____ m206
Left Arm ____ m207
Right Leg ____ m208
Left Leg ____ m209

Is any limb hypertonic?
Right Arm ____ m210
Left Arm ____ m211
Right Leg ____ m212
Left Leg ____ m213

Do you notice any involuntary movements? ..... ____ m214

Does the child seem unstable, ataxic or show titubation? ..... ____ m215

Can the child sit unaided? ..... ____ m216

Tap out reflexes at biceps, knees and ankles. Are reflexes completely absent in:
Right Arm? ____ m217
Left Arm? ____ m218
Right Leg? ____ m219
Left Leg? ____ m220

Do the reflexes seem exagerated in:
Right Arm? ____ m221
Left Arm? ____ m222
Right Leg? ____ m223
Left Leg? ____ m224

You have observed the child walk, stoop and stand up. Is there any evidence of: proximal muscle weakness? ____ m225
distal muscle weakness? ____ m226

SENSORY EXAM:

Test sensory functions only if indicated by the nature of the motor exam; i.e., only if there are motor deficits in the distribution of a peripheral neuropathy, or a spinal level such as meningomyelocele.

Is there sensory loss? ____ m227

If there is sensory loss, describe: _____

Physician: In your opinion, was this an adequate neurological exam to assess this child? ____ m228 ✓
Code: Yes = 1 No, Child Uncooperative = 2 No, Time Too Short = 3 Uncertain = 8

If Cerebral Palsy is disagnosed, enter the ICD--10 code here: ..... G____ ____ m229
(See MAF Procedure Manual, Appendix B for coding).

Additional Comments on the Neurological Exam:

Child's ID: ☐☐ ☐☐☐☐☐ ☐ ☐☐ (HF1 MC1 TQ1)

V. Anthropometry, Vision & Hearing: COMPLETE FOR ALL CHILDREN

Examiner Number: ___ ___ m230

A. PHYSICAL MEASUREMENTS:

Required for All Children.

	Child's Height (cm.):	___ ___ ___ m231
	Child's Weight (kg.):	___ ___.___ m232
	Child's Head Circumference (cm.):	___ ___.___ m233
	Child's Mid Upper Arm Circumference (cm.):	___ ___.___ m234
*Optional for Mothers Omit mother's if informant is not the mother.	*Mother's Height (cm.):	___ ___ ___ m235
	*Mother's Weight (kg.):	___ ___.___ m236
	*Mother's Head Circumference(cm.):	___ ___.___ m237
	*Mother's Mid Upper Arm Circumference (cm.):	___ ___.___ m238

Does the child's mother appear healthy? yes = 1 No, appears ill = 3 d/k, mother not present=9 ___ m239
No, not quite healthy = 2 Uncertain = 8

B. VISION & HEARING EVALUATION: ALL CHILDREN

VISION ACUITY: For 3-9 year-olds who can follow C or E chart instructions, use Landholt C chart if possible. Otherwise use E chart.

Code:
- 6/6 or better (20/20 or better) =1
- 6/9 or better (20/30 or better) =2
- 6/18 or better (20/70 or better) =3
- 6/60 or better (20/200 or better) =4
- 6/61- light perception (20 /201 thru light perception) =5
- No light perception =6
- Untestable =8

Right Eye ___ m240
Left Eye ___ m241

VISION ACUITY: For 2 year-olds and older children who cannot follow C or E chart instructions, use "fix and follow" test.

Code: 1/32 k =1, 1/8 k =2, 1/2 k =3, 6 k =4; Failed All =5; N/A, used C or E=7; Untestable =8

Right Eye ___ m242
Left Eye ___ m243

HEARING: Code: 1=Pass 2=Fail
For 2 year-old children use Downs test.
For 3-9 year-old children use audiometer.

Right Ear ___ m244
Left Ear ___ m245
Overall ___ m246

Was the audiometer used to screen this child's hearing? No=N Yes=Y ..... ___ m247

If yes, indicate the screening cutoff in dB for the particular site/day and whether the chlid passed or failed at each Hertz level given in the table below (enter 1 for pass and 2 for fail).

Screening Cutoff		Hertz 500	1000	2000	4000
___ dB	Right ear	___	___	___	___
	Left ear	___	___	___	___

Comments:

Child's ID: __|__|__ __ __ __ __|__|__ __

VI. Summary Sheet. COMPLETE FOR ALL CHILDREN. **Examiner:** For each type of problem listed below, indicate whether you think impairment is present or not. If impairment is present, indicate the diagnosis and ICD9 codes, the degree of disability (see MAF Procedure Manual for criteria), and whether or not the child has an unfulfilled need for treatment (including rehabilitation, medication, or referral for further professional evaluation and/or therapy).

TYPE OF IMPAIRMENT	DIAGNOSIS	ICD-9 CODE	DISABILITY	TREATMENT NEEDS
Is there impairment? (circle No for no or probably no, circle Yes for yes or probably yes.	see MAF Procedure Manual	see MAF Procedure Manual	1=none 2=mild 3=moderate 4=severe 8=uncertain	1=none 2=CBR 3=professional eval. 4=medication 5=2 & 3; 6=2 & 4 7=2, 3 & 4; 8=other
Gross Motor,				
No Yes m248	_____ m259	☐☐☐ m270	☐ m281	☐ m292
Fine Motor,				
No Yes m249	_____ m260	☐☐☐ m271	☐ m282	☐ m293
Hearing,				
No Yes m250	_____ m261	☐☐☐ m272	☐ m283	☐ m294
Vision,				
No Yes m251	_____ m262	☐☐☐ m273	☐ m284	☐ m295
Speech,				
No Yes m252	_____ m263	☐☐☐ m274	☐ m285	☐ m296
Seizures,				
No Yes m253	_____ m264	☐☐☐ m275	☐ m286	☐ m397
Cognition, (physician only)				
No Yes m254	_____ m265	☐☐☐ m276	☐ m287	☐ m298
Psychiatric,				
No Yes m255	_____ m266	☐☐☐ m277	☐ m288	☐ m299
Nutritional,				
No Yes m256	_____ m267	☐☐☐ m278	☐ m289	☐ m300
Other,				
No Yes m257	_____ m268	☐☐☐ m279	☐ m290	☐ m301
***Cognition,** (joint decision)				
No Yes m258	_____ m269	☐☐☐ m280	☐ m291	☐ m302

* Joint decision regarding cognition refers to the rating given by the physician and psychologist jointly, after discussion. If this differs from the physician's earlier rating do not change the earlier one.

Summary Comments:

APPENDIX 5

Clinical diagnosis of Neurodevelopmental Disorders of all severities by site and estimated prevalence per 1000.

Clinical Diagnosis	n=359 Dhaka	n=434 Dhamral	n=275 Barisal	n=163 Kurigram	n=395 Chittagong	n=1626 Total
MR only	12	11	1	-	3	27
MR with problems	20	12	2	2	4	40
CP with problems	5	4	1	-	1	11
Motor problems only	2	6	5	3	5	21
Global delay	4	3	6	3	9	25
CP only	-	1	-	-	-	1
Hearing	4	22	9	4	5	44
Hearing and speech	-	-	1	3	2	6
Xerophthalmia	4	5	-	3	4	16
Poor visual acuity	19	-	-	-	2	21
Epilepsy	6	4	3	1	-	14
Hearing, Vision	3	-	-	-	-	3
Speech delay	10	2	9	5	29	55
Total	89	70	37	24	64	284
Prevelence/1000 :	34.54	26.24	24.55	23.41	25.34	27.57

APPENDIX 6

Clinical Diagnosis of Neurodevelopmental Disorders (moderate and severe) by Site, and Estimated Prevalence per 1000.

Clinical Diagnosis	n=359 Dhaka	n=434 Dhamrai	n=275 Barisal	n=163 Kurigram	n=395 Chittagong	n=1626 Total
MR only	5	3	1	-	-	9
MR with problems	18	7	2	2	4	33
CP with problems	5	4	1	-	1	11
Motor problems only	-	2	3	-	3	8
Global delay	4	3	6	3	7	23
CP only	-	-	-	-	-	-
Hearing	1	3	-	-	3	7
Hearing + speech	-	-	1	3	2	6
Xerophthalmia	-	2	-	3	2	7
Poor visual acuity	4	-	-	-	1	5
Epilepsy	1	-	1	-	-	2
Speech only	2	1	5	3	20	31
Total	40	25	20	14	43	142
Prevelence/ 1000 :	15.52	9.37	13.27	13.65	17.02	13.78

APPENDIX 7

Breakdown of the TQP status of the original sample of 10,000 children screened in the REA study, the TQP status of those assessed in this study, including refusals for assessment.*

Population based sample of 10,300 children

TQ negative : 9456 (91.8%)	TQ positive : 843 (8.2%)
assessed : 886	assessed : 740

Ratio of screened population = 91.8 : 8.2 = 11.195

* The predictive values in Table 4.22 were corrected to represent the above ratio of TQP negative versus TQP positive population.

Note : Because the TQP + and TQP - children are not in the propotions in which they exist in the real population, the PPV for application of the OF to the entire population is based on a reconstructed sample of 740 + 886 X 11.195.

APPENDIX 8

OBSERVATION OF FUNCTION, REVISED (OFR).

Instructions: As the child and mother come into the room OBSERVE the child carry out the 7 tasks listed below.

1. Let the child walk at least 5 steps into the room and carefully observe the following:

   a) whether she is limping.
   b) whether she is bearing equal weight on both feet.
   c) whether she is walking on her toes only.
   d) do her limbs-trunk 'twist' abnormally.
   e) do her hands and feet have uncontrollable movements.
   f) have any of her hands and feet 'dried up'/become stiff.

2. Call the child to you and carefully observe:

   a) whether she can hear.
   b) is her behaviour adequate or not (eg. towards you or the mother).
   c) whether she is sullen-faced.
   d) whether she is shy.
   e) whether she can speak.

3. Ask the child to squat and pick up two small objects (a coin and a small bead) from the ground, and observe the following:

   a) whether she can open her fists.
   b) whether there is asymmetry in her grasp.
   c) whether she has difficulty in picking up the objects with her fingers.
   d) whether she has difficulty in seeing the objects.

4. Observe whether the child stands normally (if there is a problem she will put her weight on both hands to get up).

5. Ask the child: 'What have you picked up?', 'what is your name?', 'what is this?' (pointing to nose, ear, etc.), 'what is that?' (pointing to any object), and observe:

   a) whether she can hear.
   b) whether she can speak.
   c) whether she can understand.

6. Ask the child to point to different body parts (eg. eyes, nose) and observe:

   a) whether she can hear.
   b) whether she can understand.

7. Give the child paper and pencil and ask her to draw the following: scribble (for 2 year old), a circle (3 year old) a square (4 to 6 year old), a diamond (7 to 10 year old), and observe:

a) whether she has the ability to do fine work.
b) whether she can understand.

After completing the above 7 tasks, rate the child in the following areas:

Code: Pass = 1
Fail = 2
Uncertain = 3
No response = 9

Movements	____	OFR30
Fine Handwork	____	OFR31
Hearing	____	OFR32
Eyesight	____	OFR33
Speech (clarity of sounds)	____	OFR43
Speech (meaningful expression)	____	OFR35
Understanding	____	OFR36

Do you think, after your observation of the child and interview with the mother/caregiver, that she has any problem with her movements, eyesight, hearing, or understanding?

Code :No = 1
Yes = 2
Uncertain = 8

____ OFR37