

**The Nutritional Status of Disabled Children Living in Dharavi, an Indian Urban Slum
in Mumbai.**

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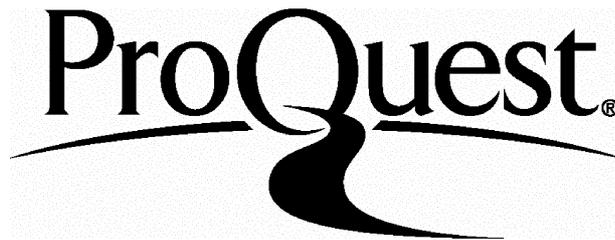
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Abstract

Limited research is available on the nutritional status of children with disabilities, and even less for those living in poverty. Research is exacerbated by insufficient guidelines to assess the nutritional status of this population. Studies in developing countries are complicated by widespread malnutrition in the general population. The aim of this study was to determine the nature, extent and probable causes of nutritional deficiencies among disabled children living in Dharavi, an urban slum in Mumbai, India, in order to develop guidelines to promote the health of these vulnerable children.

A case-control study was designed to investigate whether the nutritional status of disabled children was worse than that of non-disabled controls (siblings and neighbours). Knowledge skills and attitudes of carers towards nutrition, feeding practices and disability were studied. Anthropometry, micronutrient status, dietary intake and feeding difficulties of disabled children were compared to controls. In addition, appropriate measurements for heights of subjects with physical impairments were investigated. Results then provided information for workshops on nutrition and the management of feeding difficulties.

425 subjects were assessed. The proportion of children with disabilities with anthropometric scores of below $-2SD$ (NCHS reference) was significantly greater ($P<0.05$) than controls, e.g. 69% of children with disabilities had weight/age data below -2 Z scores compared to 42% of siblings and 47% of neighbours. Mean haemoglobin results were significantly lower ($P<0.05$) for the children with disabilities (92g/l) compared to siblings (102g/l) and neighbours (99g/l) ($P<0.05$). Relative risk analysis indicated that children with disabilities were 1.1-1.4 times significantly more likely ($P<0.05$) to be malnourished if a severe feeding difficulty was present than if no feeding difficulty was present.

Strong associations between height with: 1) Tibial length ($P<0.001$, $r=0.782$); 2) Arm length ($P<0.001$, $r=0.903$); and 3) Armspan ($P<0.001$, $r=0.966$) were found. These measurements could be used to determine a more accurate height for some children with physical impairments.

Qualitative findings of feeding practices and difficulties indicated a lack of knowledge and confidence of the carer in being able to improve the nutritional status of the disabled child. Carers gave positive feedback about the workshops. Guidelines on nutrition and good feeding practices were developed.

Dedication

I would like to dedicate this PhD to my parents ... simply for always providing me with the opportunities to realise my dreams. Thank you.

My PhD would not have been possible without the support of my parents, family and friends, which has always been deeply appreciated. A special thanks to my sister, Asma, for all her help. I am also grateful to my many teachers for their patience and wisdom.

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Abbreviations

ACT	α -Antichymotrypsin
ADP	Association for People with Disabilities
APP	Acute Phase Protein
ATDS	Attitudes Towards Disabled Persons Scale
BMC	Bombay Municipal Council
BMI	Body Mass Index
CBR	Community Based-Rehabilitation
CHVW	Community Health Volunteer Worker
CHW	Community Health Worker
CICH	Centre for International Child Health
CRP	C-Reactive Protein
DFID	Department for International Development
DMD	Duchenne Muscular Dystrophy
DPO	Disabled People's Organisation
ELISA	Enzyme Linked Immuno- Absorbance Assay
FAS	Feeding Assessment Schedule
HAZ	Height/Age
HPLC	High Performance Liquid Chromatography
ICDS	Integrated Child Development Service
ICH	Institute of Child Health
ICIDH	International Classification of Impairments, Disability and Handicaps
KAP	Knowledge, Attitudes and Practices
KSA	Knowledge, Attitudes and Skills
MMM	Mild-Moderate Malnutrition
MUAC	Mid-Upper Arm Circumference
NGO	Non-Government Organisation
NCHS	National Centre for Health Statistics
NCII	National Centre for Inclusion, India
NHD	Nutrition for Health and Development (WHO Unit)

PEM	Protein Energy Malnutrition
PSM	Preventative and Social Medicine
RDA	Recommended Dietary Allowance
RIA	Radio-Immuno Assay
RPM	Revolutions Per Minute
SES	Socio-Economic Status
SPSS	Statistical Package for Social Sciences
SSF	Sub-scapular Skinfold
SSI	Spastics Society India
TSF	Triceps Skinfold
UCL	University College London
UHC	Urban Health Centre
UN	United Nations
UNICEF	United Nations Children's Fund
VAD	Vitamin A deficiency
WAZ	Weight/Age
WHO	World Health Organisation
WHZ	Weight/Height

Chapter I.
Literature Review

In May 1998, the World Health Organisation (WHO) adopted a new policy, “Health for All in the 21st Century” (World Health Assembly, 1998). The policy presentation coincided with the 50th anniversary of the WHO; it represented a call for social justice within a framework of ten new global health targets [Box 1.1]. The vision of the WHO to motivate and encourage member states to take action and achieve common goals has the potential to put public health on the individual governments’ policy agendas (van Herten and van de Water, 1999). However, in order to make the health for all vision a reality, public health programme planners must ensure that both policy and practice is inclusive. All members of society, including people with disabilities who are often marginalised in society, must have access to information and health care for the outcomes to be considered a success.

Box 1.1. A summary of the Health for All in the 21st Century Policy put forward by the WHO (van Herten and van de Water, 1999).

Global Health Targets

1. *Health equity: childhood stunting as outcome measure*
2. *Survival: maternal mortality rates, child mortality rates, life expectancy*
3. *Reverse global trends of five major pandemics*
4. *Eradicate and eliminate certain diseases*
5. *Improve access to water, sanitation, food, and shelter*
6. *Measures to promote help for governments to achieve set health targets.*
7. *Develop, implement and monitor national Health for All policies*
8. *Improve access to comprehensive essential health care*
9. *Implement global and national health information and surveillance systems*
10. *Support research for health*

People with disabilities accounted for 290 million of the total global population in 1992. Of this figure approximately two-thirds of the disabled people lived in the developing world. Many figures are quoted to indicate disability prevalence, (this is partially due to the variable

methods and definitions used in individual country surveys), however, an expected prevalence of 4.5% of disability in a developing country is the most commonly quoted figure (Helander, 1992).

Disability is not only important by prevalence, but has a powerful human rights dimension for the individual with a disability. A fundamental difference between people with disabilities and other vulnerable groups is that people with disabilities can only claim their rights once their practical needs have been met (DFID, 2000). The additional obstacles, e.g. acquiring mobility and communication aids, have proven to be difficult to overcome for many people with disabilities in poorer communities. A recent World Bank report suggests that disabled persons may account for one in five of the world's poorest (Elwan, 1999). Under such circumstances, it may be reasonable to assume that much of this population is dependent upon others for varying degrees of physical, psychological, social or economic support (Helander, 1992). Social exclusionary practices can further isolate this population, (e.g. limited access to education or employment).

Therefore, the needs of people with disabilities have become alienated from much research and policy planning (Bury, 1990). Rehabilitation can help to eliminate and reduce dependency, thus, reversing the alienating process. In recent times, a strong body of writing has emerged by disabled people themselves, which has facilitated the changing attitudes towards planning rehabilitation services for disabled persons (Wirz, 1999). However, such changes have predominantly been in developed countries. Community-based rehabilitation (CBR) is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all disabled people (WHO; UNESCO; ILO, 1994). It is implemented through the efforts of disabled people, their families and communities. CBR has been taken up across the globe and has particularly benefited those in developing countries.

If the needs of disabled people are not met through such services, the global health targets cannot be met. Disability is closely linked with poverty, consequently for the individual with disability, community isolation will exacerbate poverty. A vicious cycle is created (DFID, 2000) affecting the individual, family and community [Figure 1.1].

Figure 1.1. Poverty and disability- a vicious cycle (Disability, Poverty and Development Report, DFID, 2000)



Children with disabilities are likely to be even more vulnerable than adults with disabilities. Anecdotal evidence suggests that children with disabilities are more likely to be neglected and malnourished than children without disabilities. In countries where under-five mortality has decreased to less than 20%, for children with disabilities it may still be as high as 80% (Harris-White, 1999).

These data suggest failure to address gaps in knowledge regarding disability. To approach this issue prevention of disability work is vital, e.g. immunisation programmes and improved sanitation and hygiene. However, work to achieve these goals must be coupled with research co-ordinating work to ensure that the needs of people with disabilities are integrated into public health programmes, (e.g. HIV/AIDS and disability, nutrition and disability). Supporting such work in part will address the inequalities that are now emerging in

communities where previously disability was seen as a separate issue that did not interact with other issues affecting communities. The importance of such research is growing to ensure a good quality of life for all as the survival rates for people with disabilities improve.

Current health priorities in developing countries are likely to remain unchanged in the immediate future, i.e. providing adequate standards of nutrition, control of communicable diseases and equitable distribution of services. All of these issues are relevant in both the prevention and the limitation of the effects of disability (Fryers, 1990).

Nutrition is a key factor for good health and overall development. It plays an important role in our physical, mental and social development. Children have the right to receive adequate nutrition independent of any other factor, (Van Leers, 1992). There has been a great deal of progress in improving the nutritional status of under-fives across the globe. Malnutrition can lead to disability, (e.g. lack of vitamin D causes rickets, vitamin A deficiency leads to nutritional blindness). Therefore, the global effort of reducing malnutrition has contributed to a reduction in preventable disabilities. For example, a study in India demonstrated how training of community health workers (CHW) for early detection of preventable and incipient disabilities was effective within the local area (Mathur *et al*, 1995). However, children with irreversible disabilities have become isolated from this process. The United Nations (UN) guidelines for nutritional surveys are an example of out-dated attitudes (UN, 1986). The guidelines state:

“Do not weigh or measure child if the child is physically deformed which will interfere with or give an incorrect measurement. To be kind you may want to measure a child and make a note of the deformity on the questionnaire.”

With this UN recommendation, it is perhaps not surprising that few studies have provided information on the nutritional status of disabled children. Furthermore, far less attention has been given to whether disability affects the nutritional status of the individual child in a developing country. This literature review aims to address the impact of disability upon the nutritional status. The main areas of discussion are:

- I. Disability Research in the Context of the Present Study
- II. The Nutritional Vulnerability of the Disabled Child
- III. The Complexities of Addressing the Needs of the Disabled Child Living in Poverty
- IV. Disability and Nutrition: Challenges in India
- V. Summary

There is enough knowledge with respect to nutrition to discuss appropriate interventions to justify screening for disabilities and investigating the nutritional status of disabled children in poor communities (Fryers, 1990). In fact, it has been estimated that 80% of the rehabilitation needs for people with disabilities can be satisfied at the level of the community (Miles, 1999).

Therefore, the aim of this study is to determine the nature, extent and probable causes of nutritional deficiencies. It is hoped this study can contribute to the gap in knowledge of disability and nutrition providing information for those who work at the community level, which is vital for achieving local health targets.

I. Disability Research in the Context of the Present Study

Today, disability research is a complex field that brings together human rights issues, social science research and medical research. Issues brought forward such as empowerment and experience all have an impact on both the understanding of the concept of disability and the direction of any development or public health work undertaken in this area. It is essential to understand these dynamics before proceeding any further.

Disability – A Myriad of Models, Classifications and Definitions.

Defining disability is a challenging process. Different models have been constructed to describe disability, which in part reflect society's changing attitudes towards people with disabilities.

1. The Medical Model

The medical model is sometimes referred to as the “Personal Tragedy Model.” A loss or impaired function in the body has a traumatic physical and/or psychological effect upon the individual, comparable to an incurable illness. The medical model expects individuals with a disability to find ways of adapting to society. The perceived needs of the disabled person are met through rehabilitation services in medical institutions (Drake, 1999; Baquer and Sharma, 1997). This model has dominated medical thinking about disability. The major flaw is the failure to accommodate permanent impairment (Fryers, 1990).

2. The Social Model

The social model, a concept that initially emerged in the 1970s, shifts the emphasis from the individual with the disability to the disabling attitudes and environment of a society. In the previous model disabled people were regarded as having limitations preventing a full participation in community life. However, disability activists, (often themselves people with impairments), have challenged the traditional understanding of disability concepts based on personal experience. They have argued it is in fact society that creates disabling barriers. The social model presents disability as a consequence of oppression and discrimination against people with impairments (Drake, 1999; Baquer and Sharma, 1997).

Concepts of the social model are very important in Community Based Rehabilitation (CBR). CBR is a model of service delivery that has embraced a comprehensive approach to understanding disability. This approach of service delivery has a developmental focus. The strategy focuses on the idea that it is the community who is ignorant of disability. Thus, the aim is encourage a change in community attitudes and behaviour for the benefit of the disabled people within a group. The programmes are designed to work through existing resources to help people with disabilities in areas such as health, education, work and legal rights. Rehabilitation is derived from the Latin “to give back dignity”, and CBR has the potential to facilitate the empowerment of people with disabilities. The CBR approach to service delivery was promoted as a vision of the WHO in 1983 as a cost-effective way of ensuring equality in health and well being for disabled people. However, this concept is not

new or unfamiliar in developing countries for which the approach was a primary target (Soeharso, 1995; Miles, 1998; Lang, 1999). This is not to imply that all developing countries are the same. However, they share a relative lack of resources and consequently a low priority of disability related problems. The CBR approach, if viewed in the context of specific cultures, has the potential to be successful in most communities where the clinical and pathological models are less likely to be useful (Marfo *et al*, 1990). A further argument for favouring the development model is the capacity to reach all people. For example, in India there are estimated to be 15 million children with disabilities. Charitable organisations which have led the way in providing services for these children only have the capacity to meet the needs of 0.6%, (Coleridge, 1993).

Shifts in attitudes are also reflected in the language used to describe disability. In 1997, the WHO reviewed the classifications for International Classifications of Impairments, Disability and Handicaps (ICIDH) originally proposed in 1980 (WHO, 1980; 1997). The definitions take account of society's role in creating further barriers to prevent a disabled person from participating in community life. The definitions are shown in box 2.2. The update provided by the WHO should not simply be regarded as an exercise in political correctness. The definitions provide a broader understanding of the concept of disability and who is disabled. It reflects the interactions of societal experiences.

The understanding of the concepts of disability and who is disabled is further illustrated in a study by Timms *et al* (1997) in Ireland. This study assessed the impact of disability awareness training using an Attitudes Towards Disabled Persons Scale (ATDS) questionnaire. The ATDS was conceptualised specifically for the North American culture, but found to be appropriate in this particular study because of similar cultural attitudes. The intervention was a two-day awareness-training programme with 39 participants from both disability and other organisations. The mean post intervention scores were higher than the mean pre-intervention score for the whole group representing a modest overall improvement in attitude. The increase was significant ($P < 0.05$) among those working in organisations with less contact with people with disabilities.

A study to assess the attitudes of CBR workers towards people with disabilities in South India was conducted by Paterson *et al* (1999) using a specifically designed culturally appropriate assessment questionnaire. This study also identified positive attitudes among the CBR workers (mainly young, female and lacking in work experience), which were influenced by the amount of education. The researchers did point out that the CBR training programmes for CBR workers had little effect on attitudes that may reflect that strategies are not directed specifically to develop positive attitudes.

A third prospective cross-sectional study explored the attitudes of non-professionals in a rural Indian community towards people with physical disabilities (Bakheit and Shanmugalingam, 1997). 82% of the 111 subjects with completed questionnaires showed positive attitudes when scored using an adapted Western questionnaire. However, a criticism of the study is that the questionnaire was administered in its original English format with simultaneous translation in to the Tamil language. Some concepts may have been lost in the translation. Age appeared to be a critical factor, with older subjects having a less positive attitude towards people with physical disabilities. Thus, this group may be a target for intervention programmes. An interesting result from the data is those with a relative with a disability were more supportive of rights for people with disabilities ($P=0.001$). However, the study was conducted in a well-serviced area with 40 of the 76 having a relative with a disability receiving rehabilitation at the local hospital, which may have contributed to the positive attitudes identified.

The perceptions held by people without disabilities can have profound effects on the adjustments of those with disabilities (Yuker, 1988). Therefore, it is important to promote positive attitudes about disability through interventions. The language used to define the construct of disability is one means of achieving this. In addition the ICIDH provide useful universal definitions that is important when looking at global prevalence.

Box 1.2. WHO's International Classification of Impairment, Disability and Handicap (WHO, 1980; 1997).

- *Health Condition*- an alteration or an attribute of the health status of an individual, which may lead to distress or interference with daily living or contact with health services. It may be a disease, injury or trauma, or reflect other health- related states such as pregnancy, ageing, stress, congenital anomaly, or genetic pre-disposition.
- *Impairment*- indicates the loss or abnormality of a body part (i.e. structure) or body function (i.e. physiological function). The physiological functions include mental functions. Abnormality here is strictly referring to a significant variation from the established statistical norms and should be used only in this sense (i.e. as a deviation from a population mean within measured standard norms).
- *Activity*- activities include simple or basic functions of the person as a whole, (grasping, moving a leg, or seeing), basic and complex mental functions, (remembering past events or acquiring knowledge), collections of physical and mental activities at various levels of complexities, (driving a car, personal social skills, interacting with persons in a formal setting).
- *Activity limitation*- (formally disability; WHO: 1980) is a difficulty in the performance accomplishment or completion of an activity at the level of the person.
- *Disability*- the root of “disability” connotes “ability”, i.e. an aptitude or skill. The disability is the limitation in the performance of the activity that derives totally from the person.
- *Participation*- is the interaction of impairments and disabilities and contextual factors, that is features of the social and physical environment, and personal factors. Participation consists all areas or aspects of human life.
- *Participation restriction*- (formally handicap, WHO: 1980) is a disadvantage, for a person with an impairment or disability that is created, or worsened, by features of the contextual factors. This includes the environmental factors, (e.g. the built environment, social attitudes, customs, rules, practices, institutions), and the personal factors that are not a feature of the disability, (e.g. age, race, gender, experience).
- *Disablement*- an umbrella term to cover all the negative dimensions of the ICIDH. In the singular the term can indicate “the process of” disabling someone; however in its plural form it is used exclusively as a replacement term to indicate impairments, activity limitations and participation restrictions.

Disability Prevalence- Facts and Figures.

A study of 55 country surveys identified disability prevalence ranging from 0.2-21% (Helander, 1992). A number of cultural and developmental factors will influence the concept of disability and consequently the prevalence figures presented for each country. It is important to have accurate and reliable information to know where to target research and programme efforts.

In 1976 the WHO estimated a 10% global prevalence of disability. However, this included temporary or reversible disability, e.g. disability caused by malnutrition. In 1992, Helander investigated disability prevalence data [Table 1.1].

Table 1.1. Global disability prevalence figures based on 1990 UN population data (Helander, 1992).

	Developed Countries	Developing Countries	Total
Total Population in millions	1207	4086	5293
Moderate-severe disabilities (%)	7.73	4.47	5.21
No disabilities (%)	92.27	95.53	94.79

The greater proportion of disability in the developed countries is likely to be a consequence of better health care and longer survival rates. Based on this data, in 1992 there was estimated to be 290 million people with disabilities in the world with approximately two-thirds living in the developing world. This figure is predicted to increase by the year 2025 with 573 million people with disabilities in the world, of which 435 million are expected to be living in the developing world. There is likely to be an urban bias in the proportion of disabled people (Coleridge, 1993). This is explained by considering the causes of disability shown from the medical model perspective in table 1.2. Trauma or injuries (accidents) are estimated to account for approximately 17% of all disabilities (Helander, 1992; DFID, 2000), and are frequent occurrences in the urban setting.

This information is an indication of the large numbers of people involved globally who need to have the attention of public health and development programmes for the international targets to be met.

Table 1.2. Causes of disabilities and estimated prevalence of moderately and severely disabled people in the world, estimates for 1990 (Helander, 1992).

Causes of disability	Global suggested ranges of estimates of the prevalence of moderate-severe disability (in millions)
1. Congenital or perinatal disturbances <ul style="list-style-type: none"> • Mental retardation • Somatic hereditary defects • Non-genetic disorders 	10-20 10-25 15-20
2. Communicable diseases <ul style="list-style-type: none"> • Poliomyelitis • Tracheoma • Leprosy • Other 	5-10 8-10 3-4 30-40
3. Non-communicable diseases	70-80
4. Functional psychiatric disturbances	15-20
5. Alcoholism and drug abuse	25-30
6. Trauma/Injury <ul style="list-style-type: none"> • Traffic accidents • Occupational accidents • Home accidents • Other 	15-20 10-12 15-20 2-3
7. Malnutrition	7-10
8. Other	2-3

Note: World population in 1990 was 5300 million

Disability- The Influence of Culture and Experience.

Successful outputs from any programme will require an intrinsic understanding of culture and experience with respect to disability. The simplest definition of a disabled person is one who

is regarded in his society as disabled because of differences in appearance or behaviour, (Helander, 1992). Therefore, programme implementation that both meets the needs of disabled people and protects their human rights must be built on an understanding of local beliefs and attitudes. Communities are not static or homogenous. They are all variable and the dynamics must be understood.

The first question that should be asked is “Who is considered disabled within a particular cultural setting?” For example, in a farming village where physical labour is required a man with severe physical impairments may be considered more disabled by his community than a man with learning impairments who may still be able to carry out the tasks on the farm. In contrast, in a city where the better paid jobs may require literacy, the man with physical impairments may not be considered as disabled by the community around him as a man with learning impairments.

Attitudes arise from specific experiences and emotions driven by cultural beliefs. These experiences can have an enormous impact upon the lives of people with disabilities, both adults and children alike. Harper (1995) reviewed several studies focusing on children’s attitudes towards children with physical differences among youth from Western and non-Western cultures. These studies used picture-based interviews showing children with different physical impairments and features. The children interviewed were asked to rank which child they most preferred. Factors such as age, sex, contact, family attitudes, attribution (child’s view on how the disability happened), chronicity, duration and culture have all been documented as influential in understanding the social psychology of disability. The studies are summarised in table 1.3.

Table 1. 3. Comparison of rank orders of physical disabilities among Western and non- Western countries (Harper, 1995).

Study Group	Most 1st	2nd	3rd	4th	5th	Least 6th
Richardson (US) n=3000	Normal	Crutch	Wheelchair	Hand	Facial	Obese
Harper (US) n=358	Normal	Crutch	Wheelchair	-	Facial	Obese
Harper (US) n=60, disabled	Wheelchair	Crutch	Wheelchair	-	Facial	Obese
Harper (Nepal) n=96	Normal	Obese	Crutch	Hand	Facial	Foot
Davidson/ Harper (Antigua) n=39	Normal	Obese	Crutch	Hand	Facial	Foot
Sanchez/ Harper (Yucatan) n=300	Normal	Obese	Facial	Hand	Crutch	Foot
Harper <i>et al</i> (New Zealand-Urban Maori) n=78	Normal	Wheelchair	Crutch	Hand	Obese	Facial
Harper <i>et al</i> (New Zealand-Rural Maori) n=77	Normal	Obese	Wheelchair	Hand	Crutch	Facial

Note: Normal was the term used by the researchers to described non- physically impaired children.

Facial refers to facial disfigurement; Hand refers to a missing hand; Foot refers to impairment of foot.

Richardson *et al* (1961) noted sex differences in relation to preferences with boys having low preferences for children with functional impairments and girls least liking children with facial disfigurements.

The more recent studies by Harper *et al* (1985, 1986) attempted to explore attitudes in relation to a situation context and concluded it was not possible to make general statements about preferences without considering the situation, (e.g. Who would you like to play catch with? Who would you like to play chess with? Etc). In each of the countries studied, cultural factors were also an influencing factor of preference. For example, in the USA obesity has negative associations and obtained the lowest ranking. In contrast, in some countries affluence can be equated with food availability and body size, signalling wealth and power. Children in Nepal selected obesity as more preferable. In the Nepalese, Antiguan, Yucatan and Maori populations children with mobility impairments were often ranked as least preferred. Within labour-focused environments, physical impairments will limit the economic earnings, which may affect preference.

Children with visible physical differences are known to experience difficulties socially with peers. Cultural factors play a role in their experiences and must be taken in to consideration when developing programmes to facilitate their participation in society.

When working with carers it is also important to consider the experiences and feelings of the carers. Maternal expectations on child development will also vary in different cultures. Pachter and Dworkin (1997) interviewed 255 mothers attending a paediatric clinic in the USA using semi-structured interviews. Maternal expectations of when a child was to achieve a social milestone were different in different cultures, e.g. Puerto Rican mothers expected children to attain these milestones at a much later stage.

In some cultures a disabled child may be considered to be sick; consequently the mother will wait for the condition to improve before seeking further medical advice or seek medical advice in search of a cure, which is very expensive (King and Burgess, 1993). Resignation

towards disability as opposed to acceptance can also delay seeking rehabilitation. This may happen in cultures where disability is believed to be the result of a past sin or a curse.

The experiences of disabled people will differ depending on the different cultural environments. Rejection of a disabled child can happen in situations where the child is seen as an economic burden. In some cultures, such as the Indian culture, the disabled girl child may be more vulnerable than the disabled boy child (Coleridge, 1993). Rejection is a dynamic of prejudice or ignorance. Disability is closely associated with poverty as demonstrated in figure 1.1 Such experiences can also contribute to the vicious cycle, (e.g. social exclusion leading to lost opportunities in the employment market).

Programmes must carefully assess the needs of the disabled person in context of the specific cultural environment and take into account individual experiences. Therefore, the term “needs” is not only those assessed by the researcher, but also include the felt and expressed needs by the individual with disabilities and in the case of infants their carers.

A cross-sectional screening survey in rural Thailand covering 1836 households identified 53 children with disabilities after medical confirmation (Pongprapai *et al*, 1996). With respect to health seeking behaviour, 20 of the carers claimed that none had been sought citing reasons such as cost, inaccessibility and cultural beliefs. Of the remaining, 53% (n=17) sought traditional treatment only, 35% (n=12) had sought out Western treatment and the remainder had sought out a mixture of both. The survey indicates the potential for a CBR programme to improve services for people with disabilities in the area.

A childhood disability and family needs survey was conducted in China (Chen and Simeonsson, 1994) using a format designed for a previous study in the USA. A total of 101 families from both an urban and a rural setting were recruited for the exploratory study investigating expressed and felt needs. The children in the urban community were from a higher socio-economic status (SES) and were students at a special school for hearing impaired children. In contrast, the children from the rural communities had mixed disabilities (mainly developmental disabilities) and either went to a mainstream school or stayed at home.

The urban families expressed significantly more needs than the rural families ($P < 0.01$). The top three expressed needs for the urban families were seeking specialist help, locating a doctor and information on how to teach the child. The top three expressed needs for the rural families were information about the child's condition, paying for therapy and information about present services. Action for basic necessities is required in the rural setting, whereas information of specialist surveys is a priority for the urban setting. Table 1.4 indicates the different concerns and problems felt by the families.

Table 1.4. Percentage of expressed problems and concerns felt by families of children with disabilities (modified from Chen and Simeonsson, 1994).

	Urban Families n=46 (children with hearing impairment) (%)	Rural Families n=55 (children with developmental disabilities) (%)
Family problems		
• Financial	47.6	70.9*
• Child with disability	71.7	89.1*
• Family conflict	4.3	5.5
Family concerns		
• Health	26.1	63.6**
• Education	39.1	67.3**
• Marriage	28.2	56.4**
• Occupation	76.1*	59.9
Family stress		
• Burden	41.3	63.3*
Family feeling		
• Shame	6.5	34.5**
Received support		
• Welfares	13.0	47.3**
• Relatives	43.5	54.5
• Neighbours	2.2	40.0**
• Government	19.6	47.3**

*Note: ** Significantly different ($P < 0.05$); * Significantly different ($P < 0.01$)*

These concerns require consideration in intervention research.

Disability- Advocacy and Research

The understanding of culture and experience, thus the involvement of people with disabilities, is important in research and development. The disability movement has been active in advocacy in order to prevent people with disabilities becoming invisible in policy planning. The human rights dimension is a powerful one and cannot be pronounced enough.

“Disability [is] a Human Rights issue. So long as people with disabilities are denied the opportunity to participate fully in society, no one can claim that the objectives of the Universal Declaration of Human Rights have been achieved.” (B. Lindqvist, UN Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, 1999) (Source: DFID, 2000).

In 1993, the UN adopted the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. The rules imply a commitment from member states to take action ensuring the rights of disabled people. There are multitudes of disabled peoples’ organisations (DPO) that campaign for equal opportunities. The importance of positive language is reflected here with the focus on the ability of the individual rather than the disability. As previously mentioned, disabled people have themselves produced a strong body of writing to describe their experiences, for example, Oliver (1990). An examples of good practice is seen in Uganda where people with disabilities have achieved a greater level of political representation than elsewhere, with representation at both the national and local levels (Ashton, 1999). However, the Ugandan achievement is facilitated through a quota regulation system..

However, for the majority of people with disabilities in the developing world such achievements are still a long way off. Parents are not receiving sufficient help with the care, education and training of their disabled child (Mariga and McConkey, 1986). The basic barriers must still be overcome with adequate access to health, education and employment

opportunities to permit participation in society. Currently, it is estimated that only 2% of people with disabilities in the developing world have access to appropriate services (Despouy, 1993).

Further research is necessary to address the emerging issues. At present, much of the understanding of disability in the context of different cultures and the work carried out by DPOs and non-government organisations (NGO) is largely found in the grey literature. Formal evaluations of CBR programmes are not yet common occurrences. An evaluation by O'Toole (1998) of a CBR programme for pre-school disabled children in Guyana is one of the few examples that can be cited.

Successful research requires participation of disabled people and their families, particularly, if the researcher is to avoid cultural stereotypes. In recent times culturally appropriate models of CBR have arisen, for example the Project Projemo in rural Mexico. However, others have been unable to replicate this example due to a failure in taking into consideration the different cultural settings (Wirz, 1999). Communication across cultures is always subtle and complex. Some concepts are not directly translatable into other languages. This was the flaw in the previously described study by Bakheit and Shanmugalingam (1997) when investigating the attitudes of non-professionals towards disability in rural India. Timms *et al* (1997) also concluded it was necessary to develop an ATDS specifically for the Irish population rather than be reliant upon the North American scale of attitudes. It is valuable under such circumstances for the researcher to use local personnel as facilitators.

Large scale household surveys of disability for research purposes are few. They are expensive to conduct when seeking out less than 4% of the population for possible studies. Studies often require a great deal of co-operation and motivation, as the subject matter is very personal. The inclusion of a disability question in other public health surveys will provide valuable information in communities where less is known about disability, and a starting point for larger possible studies. A current household survey in Nepal has incorporated questions about disability into the main survey that will provide information in an area where little is known

about disability type and prevalence (Professor A. Costello *et al*, Centre for International Child Health, London, and MIRA, Nepal (local NGO); survey in progress).

Research in the pursuit of knowledge alone is difficult to justify in very poor communities. Guidelines for attempting research should be in order to investigate suitable interventions, assess the size of the problem as a target for potential development and for prevention. Prevention of impairments is important. With improved immunisation programmes a global decrease in impairments caused by poliomyelitis, for example, is inevitable. Clearly, prevention of disabilities should not be the only focus, as it will do nothing to ameliorate the lives of those living with disability. Unfortunately, a search of the scientific literature indicates little collaboration between major current public health issues and disability.

It is the role of the public health researcher to gather data of the assessed, expressed and felt needs of people with disabilities and their families. This is not to imagine that all people with disabilities have the same needs. Experiences will differ according to age, gender, community, religion and SES. However, until we investigate and implement needs the status quo is left unchallenged preventing further advocacy work in poorer regions.

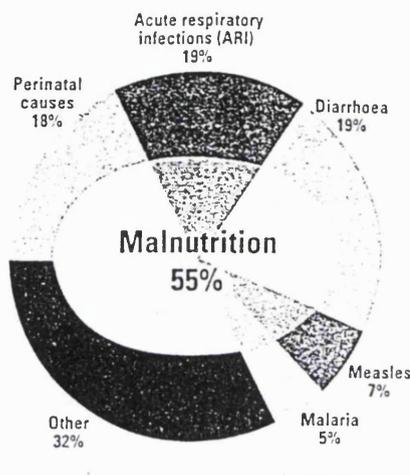
In the context of the present study, nutritionists need to be more aware of vulnerable groups within a community and be provided with adequate guidelines for nutritional assessment and care. The UN nutrition surveys guidelines (1986) need to be updated. An annotated bibliography of *Caring for the Nutritionally Vulnerable During Emergencies* (WHO, 2000) makes several references of literature listing people with disabilities, however, the information is insufficient for guidance. It is also in the interest of the NGOs and DPOs to further their understanding of nutrition. The exchange of information is invaluable.

II. The Nutritional Vulnerability of the Disabled Child

Overcoming global malnutrition is still a challenge to public health professionals as we enter the new millennium. Malnutrition, often referred to as the silent emergency, is estimated to

effect 20% of people living in the developing world (NHD/SDE/WHO, 2000). It is implicated in approximately half of all child deaths [Figure 1.2].

Figure 1. 2. Malnutrition and child mortality (State of the World's Children 1998, UNICEF)



Note: WHO estimates that malnutrition was associated with over half of all child deaths in 1995.

Without intervention malnutrition can lead to death, disease and disablement. Helander estimated malnutrition led to disability in 7-10 million people worldwide in 1990 (Helander, 1992).

A poor nutritional status is not simply equated with a lack of food, but with the interaction of the individual's diet, health status and environment. Therefore, appropriate treatment is not only medical, but is also related to the understanding of societal factors.

Recognising and understanding malnutrition is the first stage of intervention. Pelletier (1994) reviewed 28 nutrition reports from 10 developing countries to examine the potentiating effects of malnutrition on child mortality. The evidence supports the notion that an inverse relationship exists between mortality and anthropometric measures of nutritional status. Previously, the major focus was on cases of severe malnutrition because it was assumed that mild-to-moderate malnutrition (MMM) had no consequence on child mortality. However, a study by Trowbridge and Sommer (1981) identified that the presence of MMM was

associated with a modest elevation in mortality in a study conducted in Bangladesh. Mid-upper arm circumference data (MUAC) of less than 12cm, normally indicative of severe malnutrition was related to a sharp increase in mortality; and a MUAC between 12-12.9cm, normally indicative of MMM showed a modest elevation in mortality. In Pelletier's review, eight studies examining weight-for-age data confirmed this exponential relationship. Using data from 53 countries, the review suggests that of the child deaths with malnutrition as an implicating factor, 83% were estimated to have had MMM.

There are many causes of malnutrition including inequalities in food distribution, infections, drought, war, neglect, anorexia, poverty and social disadvantage (Waterlow, 1992). Protein-energy malnutrition (PEM) and micronutrient deficiencies, (in particular, vitamin A, iron and iodine) are different types of malnutrition.

PEM affects every fourth child worldwide: 26.7% are underweight and 32.5% are stunted. The majority, approximately 70%, live in Asia (NHD/SDE/WHO, 2000). Kwashiorkor is a severe form of PEM with obvious clinical symptoms such as swelling of the arms and legs (oedema), apathy and changes in the skin and hair caused by a sudden deprivation of food. Marasmus is a second severe form of PEM with obvious severe muscle wasting and loose skin due to the depletion of fat and muscle tissue caused by chronic malnutrition (Waterlow, 1992).

Vitamin A deficiency (VAD) is a major public health problem in at least 78 countries. Currently, 350 000 cases of childhood blindness is thought to be as a result of severe VAD (Underwood, 1994). Xerophthalmia is a syndrome of clinically observable symptoms due to VAD. Night blindness, and mild forms of conjunctival xerosis and corneal xerosis are all reversible symptoms. Severe symptoms such as keratomalacia are only partially reversible or irreversible. The association between vitamin A deficiency and increased risk of mortality and morbidity is well established (ACC/SCN, 1993). A large clinical vitamin A supplementation trial in Ghanaian children showed a mortality decrease of 19% in the supplemented group, (mainly because of a reduction in mortality from diarrhoea disease) (Ghana VAST study team, 1993).

Iron deficiency is the most common nutritional deficiency worldwide and is the main cause of anaemia. There is a high prevalence of iron-deficiency anaemia in school children and pregnant women. Children born to iron-deficient mothers can have premature birth, low birth weight, poor physical development and is likely to be associated with impaired cognitive development (Idjradinata and Pollitt, 1993; Grantham-McGregor S and Ani, 2000). Anaemia contributes to 20% of all maternal mortality (NHD/SDE/WHO, 2000). Many efforts have been made to reduce iron deficiency, for example, supplementation and deworming programmes for the facilitation of iron absorption. There is also an interest in iron pots for increasing the iron content of foods when cooking (Reilly, 1998).

Iodine deficiency disorders affect the growth and development of up to 800 million people despite being one of the most easily preventable of deficiency disorders (Hetzel, 1989). Disorders include goitre, miscarriages, neonatal and juvenile thyroid deficiencies, mental impairments and dwarfism. Programmes, such as iodisation of salt, are possible means of intervening to control iodine deficiency disorders in iodine deficient areas. Universal salt iodination was adopted in 1993 and has contributed to a fall in iodine deficiency related disorders.

Other micronutrients such as vitamin D and calcium are also important with regards to malnutrition, in particular with respect to disability. Vitamin D and calcium deficiencies are related to disorders of the bone, e.g. nutritional rickets or osteoporosis, which can both cause impairments or further exacerbate present impairments. Vitamin D is obtained through the diet and is also synthesised in the skin by exposure to sunlight. However, deficiencies are observed even in regions with a lot of sunlight. Therefore, much work is still needed to understand more fully the interactions of these micronutrients in the body (Thacher *et al*, 1999; Walter *et al*, 1997).

Nutrition risk factors throughout life vary. For example, low birth weight, early anaemia and growth retardation in new-borns are consequences of poor maternal health and nutritional status (Bhargara *et al*, 1991). In adolescents PEM, iron and folate deficiency, VAD, iodine deficiency and calcium deficiency can lead to a delay in the growth spurt, stunting, anaemia

and inadequate bone mineralisation (Baker *et al*, 1999). The elderly population is also vulnerable to illnesses like osteoporosis, increased fractures and other diet related illnesses (Munro and Schlierf, 1999). Risks from obesity related illnesses like heart disease in some populations have also been observed (Popkin and Doak, 1998).

The Nutrition for Health and Development (NHD) unit of the WHO aims to support nutrition research and policy worldwide (2000). Women's health, ageing, child and adolescent health, immunisation, food safety, HIV/AIDS, mental health, non-communicable diseases, blindness prevention, chemical safety, oral health and reproductive health are areas noted for collaborative work. Vulnerable groups such as women, (especially those of child bearing age), young children, people in emergencies and the elderly, (often with disabilities) are clearly important targets for nutrition programmes.

A symposium on the nutritional vulnerability of older people in developing countries (HelpAge International and LSHTM, 1997) discussed the special nutritional needs of the elderly. It is estimated that 61% of the elderly live in the developing world and with improvements in health the numbers are set to rise. However, the majority of this population do not retire despite chronic and disabling illnesses. With increased migration to urban areas, the support from the extended family is also not available for some. This population requires attention due to difficulties with managing harder textures of food because of poor dentition, in addition to an increase in vitamins and minerals and less energy. The need for more work in this area is slowly being recognised.

The NHD/WHO are addressing issues through nutrition like mental health and blindness that will prevent disabilities. However, there is not as yet any consensus on promoting additional research work on the health of people with disabilities who, as previously discussed, are marginalised and may be considered an at risk group for malnutrition. The following section of this review aims to determine whether there is an argument for more focus on disability and nutrition in public health.

The Importance of Food for all Young Children

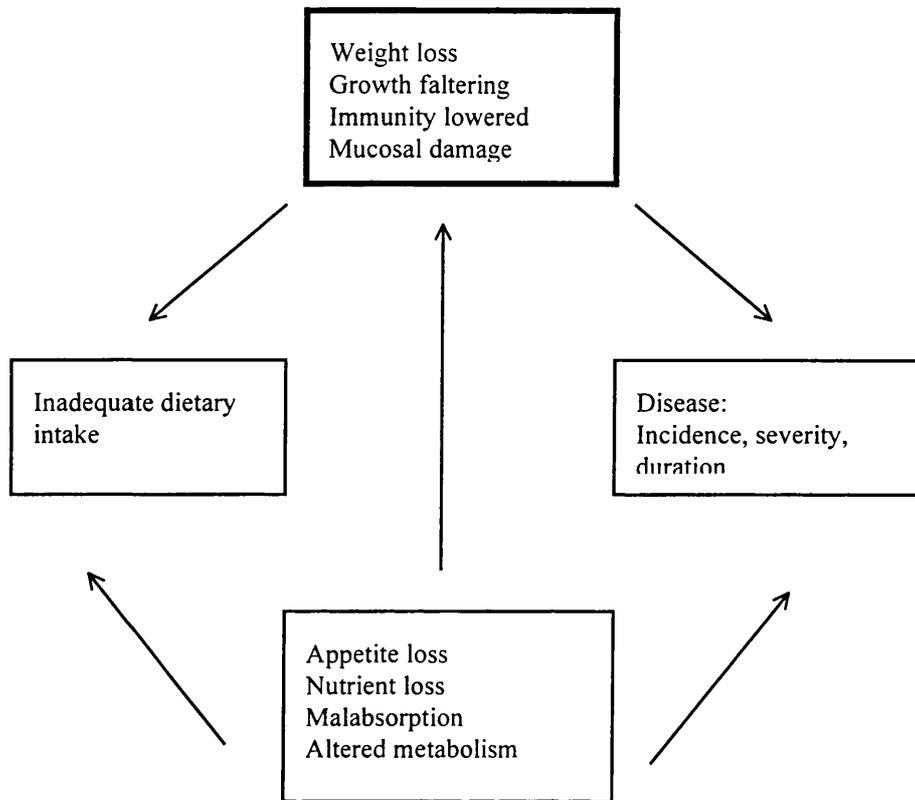
Adequate nutrition is essential for overall health and well being. In young children, a healthy diet contributes to good physical growth and mental development. In addition, food plays an important role in the development of the child not only by the nutrient intake, but also through the process of learning to eat and drink. It is in these early stages that the young child learns the fundamental skills required for oral control, postural development, language learning, social interaction and independence (Winstock, 1994). For most children it is a natural process with little attention required by the carer, however, for children with disabilities it can be a challenging learning process. The nutritional status is a dynamic interaction between 1) the nutrient intake; 2) the current health status; 3) the environment and, in the case of the child; 4) the caregiver. This is particularly important when discussing nutritional issues for the disabled child. Background information for both the role of nutrition and the process of eating and drinking is discussed.

1. The Role of Nutrients

The body requires nutrients to build tissues, provide a strong immune system and produce energy. Inadequate dietary intake leads to growth faltering, disease and disablement [Figure 1.3].

The inadequate dietary intake and disease cycle is commonly observed in the developing world. The poor nutritional intake results in a lowered immune defence system. The resulting disease further speeds the loss of nutrients and is thought to suppress appetite, (the mechanism for appetite suppression is not clearly defined at present) (ACC/SCN, 1993).

Figure 1.3. Inadequate dietary intake/ disease cycle (ACC/SCN, 1993a)



It was in the 1960s that Scrimshaw *et al* (1968) first raised interest in the synergistic relationship between nutrition and infection. The main components of the body's response to infection include; production of cytokines (components of the immune system), anorexia (responsible for secondary malnutrition), pyrexia, catabolic losses, malabsorption, production of acute phase proteins and decreased circulating concentrations of micronutrients (Tomkins, 1992). The relationship between immunity and nutrients operates in both directions. In some situations, a reduction of nutrients may protect the body against infection (e.g. parasites may require the nutrients for growth), or an increase in micronutrients may be required (e.g. vitamin A supplementation has been found to potentiate cytokine production in vitamin A deficient children) (Bhaskaram *et al*, 1989). The interactions involved are complex (Filteau and Tomkins, 1994) and current assessment procedures can be misleading (Filteau *et al*, 1995, 1993). Vitamin A supplementation trials with respect to measles, diarrhoea and HIV have been conducted with mixed results. The Ghana VAST trial found reductions in mortality by 19% among children in a vitamin A deficient population (Ghana VAST Study Team,

1993). However, a vitamin A supplementation trial among pre-school children in South India found supplementation was not as beneficial in reducing common respiratory and diarrhoea morbidity in an area with relatively good health services (Ramakrishnan *et al*, 1994). Supplementation programmes with respect to disease must be thought through carefully in order not to waste scarce resources (Filteau, 1999).

The data does emphasise the importance of vitamin A in the maintenance of respiratory and gastrointestinal epithelial cell integrity that has led to studies of vitamin A in cystic fibrosis (Duggan *et al*, 1996; Lancellotti *et al*, 1996). This health condition is associated with malabsorption of fat-soluble vitamins (i.e. vitamins A, D, E and K) and inflammatory stresses in the respiratory epithelial linings causing deficiencies in vitamin A; however, very few studies have investigated infection and nutrition in children with disabilities. One example is a study investigating vitamin A supplementation in children with Down Syndrome, an inherited learning disability (Palmer, 1978). Affected children are prone to increased infections and nutritional supplementation is often recommended, although benefits have yet to be proven (Ani *et al*, 2000). The study by Palmer followed 23 children with Down syndrome and sibling controls to observe the benefits of vitamin A supplementation on infection rates. Some benefits were noted over a 6-month period. However, the study is poorly described with respect to methods and outcomes.

Clearly, the relationship between dietary intake and disease cycle is complicated. However, without interventions, deficiencies and diseases can lead to further disablement. Supplementation of micronutrients is no doubt beneficial in preventing impairments in deficient areas, (e.g. nutritional blindness by VAD). Iron deficiency is also commonly prevalent in poor communities. A prevalence study of iron deficiency anaemia in children (6-60months) living in urban slums of Karachi, Pakistan identified 63% of children as anaemic (Molla *et al*, 1992). The study used haemoglobin (cut-off below 110g/l, WHO criteria) to indicate anaemia. Iron deficiency is associated with psychosocial, economic and biomedical disadvantages thus, children are at risk for poor development. Evidence suggests a positive effect of iron treatment on cognition in anaemic children. The many studies conducted in the developing world are also thought to be relevant for children in the higher income countries.

Pollitt (1994) concluded in a review that iron deficiency anaemia among American children living in poverty was a public health problem. However, further research is required before a true causal relationship between iron deficiency and cognitive development can be established (Grantham-McGregor and Ani, 2000). In contrast, the relationship between iodine deficiency and learning disabilities is more established as shown by studies conducted in India and Bangladesh (Tiwari, 1996).

No formal study has documented cognitive development and iron deficiency among disabled children. However, informal observations at Chailey Heritage, a specialist rehabilitation and development centre for children with complex disabilities, have been made. Children were supplemented with a course of iron and folate. Staff found children were more alert and responded better in classroom situations (informal conversation with Dr. Khan, the Director of Chailey Heritage, 1998). However, a formal research study is required.

There are associations between nutrition, cognitive performance, apathy and mental fatigue, but further research is required to clarify the mechanisms (Salmon, 1994). In well-nourished children eating lunch led to improved transient performances in some cognitive tasks (Craig, 1986). While in another study, missing breakfast was shown to adversely affect children already stunted or wasted in cognitive performance. In contrast, well-nourished children were not affected or were positively affected with respect to cognitive performance (Simeon and Grantham-McGregor, 1989). The results suggest short-term metabolic changes interacting with the health status of the child.

The role of vitamin D has also been studied in relation to physical growth, particularly with respect to bone metabolism and its interaction with calcium (Gupta, 1996), and a few studies in relation to muscle weakness (Rimaniol *et al*, 1994; Grady *et al*, 1991; Lee *et al*, 1989). In the past dietary intake of vitamin D was considered less important than the synthesis of vitamin D through sunlight exposure, although both situations are researched today. The vitamin can be synthesised endogenously in the epidermis of the skin from 7-dehydrocholesterol by the action of ultra-violet light (van den Berg, 1993). It is recommended

that children spend at least 10 minutes of the day outside exposed to sunlight to obtain sufficient vitamin D (King and Burgess, 1993).

In the UK, an Infant Feeding in Asian Families survey (Lawson *et al*, 1999) analysed plasma vitamin D levels and dietary records among infants of Indian, Bangladeshi and Pakistani origin. The vitamin D levels were lower in all three groups compared with children of a similar age in a National Diet and Nutrition survey. The proportion of low vitamin D status children (cut-off below 25nM for 25-hydroxyvitamin D₃) was significantly higher (P<0.05) in the Pakistani group. Between one-third and a half of children with low vitamin D status also had a low haemoglobin. After multiple regression analysis, the four main factors associated with low plasma vitamin D was failure to take a supplement, low haemoglobin, low ferritin (iron) and consumption of chapati. It has been postulated that the high phytate content of chapati may interfere with the enterohepatic circulation of vitamin D. In infants the vitamin D intake through breast milk is dependent upon the vitamin D status of the mother (Specker *et al*, 1985; Atiq *et al*, 1998), therefore maternal vitamin D status and breastfeeding patterns also require investigation. Exposure to sunlight was found to be similar to that of non-Asian children in the UK. It has been proposed that pigmented skin may require longer exposure.

Deficiencies of vitamin D are associated with osteomalacia, osteoporosis and rickets (metabolic bone diseases). However, cases are identified in regions of high sunlight exposure such as Nigeria and India (Menon *et al*, 1994; Walter *et al*, 1997; Thacher *et al*, 1999). Osteoporosis is highly prevalent among the Indian elderly population, probably due to a malabsorption of calcium due to a sub-clinical vitamin D deficiency (Gupta, 1996). Increased disability was a risk factor for vitamin D deficiency in an American study of the elderly population (Semba *et al*, 2000). A study of vitamin D status among otherwise healthy subjects in Delhi identified a low prevalence of vitamin D (Goswami *et al*, 2000). Factors such as low calcium intake and high dietary phytate were associated with bone mineral metabolic imbalances. Singh *et al* (1992) discussed the higher prevalence of rickets in Indian cities as compared to the rural areas. The Indian diet contains very little vitamin D thus, the population is reliant upon sunlight exposure. The lack of exposure due to pollution and lifestyle in the industrial cities may in part explain a higher incidence of rickets. The authors

also noted the cultural resistance to exposure of too much sunlight for fear of obtaining a dark complexion.

The studies from Nigeria (Walter *et al*, 1997; Thacher *et al*, 1999) indicate the role of dietary calcium intake and vitamin D in rickets needs to be investigated further in order to inform policy on prevention of rickets in tropical climates.

Studies examining further impairment due to vitamin D deficiencies in children with disabilities are limited. The main studies investigate vitamin D status and bone mineral density in relation to anti-convulsant therapy in children with cerebral palsy (Baer *et al*, 1997; Henderson *et al*, 1995). Studies in this area are particularly important in relation to ambulatory status. The studies suggest ambulatory status is important in relation to abnormalities in bone status, calcium and vitamin D. However, more research is required to identify specific mechanisms. It may be possible to investigate vitamin D as a function of activity. Anecdotal evidence suggests children with mobility problems and a lack of mobility aids may have less exposure to sunlight. However, there are insufficient studies to draw any further conclusions in this area at present.

In the present review, only a few key examples have been illustrated, but all macronutrients and micronutrients play important roles in the body. The FAO/WHO/UNO committee (1985) has made recommendations on the quantities required. This is valuable information for the health of all young children, including children with disabilities. However, only limited information on the specific special nutrient needs for some children with disabilities is available. A little information exists for children with cerebral palsy and this is mainly in relation to gastrostomy intervention (tube feeding) (e.g. Stathopoulou *et al*, 1997). The specific nutrient needs of children with disabilities is a grossly under-researched area.

2. The Process of Eating and Drinking

The process of learning to eat and drink provides the foundations for the pre-requisite skills that are required for other aspects of child development [Box 1.3].

Box 1.3. Skills developed through the process of learning to eat and drink (Yousafzai: Disability and Impairment Course, Centre for International Child Health, London, 2000)

- | | |
|-------------------------------|--|
| • Oral control | The patterns of movement of lips, tongue, jaw, breathing, etc., provided whilst eating strongly influence the development of precise movements necessary for speech and control of saliva. |
| • Postural development | Mealtimes provide opportunities for the development of posture, head control, hand/eye co-ordination. It is important that it is achieved in a developmentally appropriate way, i.e. normally rather than allowing abnormal postures and movements to prevail. |
| • Learning language | Considerable language interaction occurs at mealtimes allowing vocabulary building, concept development, etc. |
| • Social interaction | Mealtimes are ideal settings in which rules of social behaviour are learned and are a focus for ritual, customs and interactions throughout life. |
| • Social integration | Integration in to mealtimes is easier as the child's eating competence grows. |
| • Independence | Giving choice and control at mealtimes allows the child to develop self-esteem, independence and his own identity. |

The development of these skills occurs through a complex and dynamic bio-psychosocial process involving emotions, sensory-motor skills, cognitive skills and neurological skills (Morris, 1987; Arvedson and Brodsky, 1993).

There are three main stages involved in the intake of food and drink: 1) the ingestion of food; 2) the swallow reflex; and 3) the digestion of food. The first stage is a voluntary action and the subsequent two stages are involuntary actions. Table 1.5 summarises the development of feeding skills from birth.

Table 1. 5. Learning to eat from birth to 4 years of age (Wickenden: Disability and Impairment Course, Centre for International Child Health, London, 1998)

Oral Activity	Foods	Talking	Age
<p>1. Sucking</p> <p>Rhythmical, jaw, lips and tongue swallowing automatically synchronised with breathing reflexes present. Nutritive and non-nutritive suckling.</p> <p>Breast or bottle fed.</p>	Liquids	Cooing, gurgling, crying	Birth
<p>2. Suckle drink, Suckle chew.</p> <p>Lowered tongue-tip, lips often open but active-dribbly, mashing movement, jaw and body of tongue involved, oral reflexes decreasing-except for gag, feeder cup, drooling, teeth erupt, reflex biting.</p> <p>Finger feeding self and being fed.</p>	<p>Weaning</p> <p>Thickened liquids</p> <p>Separate textures</p> <p>Introducing new tastes</p>	Babble	<p>6 months</p> <p style="text-align: center;">↓</p> <p>1 year</p>
<p>3. Chewing</p> <p>Lips closed, accurate tongue-tip movement, circular side-to-side food better controlled, oral and pharyngeal stages of swallow separate and volitional controlled biting, covered cup</p>	<p>Hard/chewy foods</p> <p>Neophobic refusal</p>	<p>First words</p> <p>Sentences</p>	
<p>4. Mature eating and drinking</p> <p>Food kept in mouth, tidy eating, food retrieved, chews well, open cup.</p> <p>Social aspects of mealtimes. Feeding self well.</p>	All types of foods. Variety.	Clear speech	4 years

In stage 1, primitive reflexes are observed [Box 1.4]. For example, the rooting reflex that enables the baby to locate the nipple or teat for milk. Early sucking can be nutritive (a slow and powerful suck accompanied by the intake of milk), or non-nutritive (a shallow and fast sucking movement with no milk intake). The infant is in a reclined position, which is safe during this stage of anatomical development when protective reflexes against choking are

present. However, as the anatomical structures develop and the infant begins to sit up, feeding in the reclined position becomes unsafe.

When the infant develops greater head control, the reflexes become more refined. The infant begins to mange different textures. However, in the early phase it is difficult for the infant to manipulate mixed textures (e.g. baked beans) and separate textures are preferable (Gisel, 1991). Initially infants prefer sweet tasting foods and neophobic refusal of new flavours can be observed. By approximately 4 years of age, mature eating and drinking begins. Mature reflexes replace the primitive reflexes.

Box 1.4. Summary of primitive reflexes (adapted from Winstock, 1994)

- | | |
|-------------------------------|---|
| • Rooting reflex: | Birth to 3-5 months
Enables location of nipple or teat. |
| • Gag reflex: | Protective mechanism, present throughout life. Very sensitive in the first few months after birth.
Premature representations, weakens as solids are increased |
| • Suck-swallow reflex: | Birth to 5-6 months |
| • Bite reflex: | The normal type is from birth to 3-5 months and is then replaced by a volitional bite. The abnormal reflex may be a spasm of the jaw muscle. It is more likely to occur when the child is bending forward with arms flexed and hands fisted. It can be stimulated if using a spoon centrally presented. Jaw is clenched. Can be associated with hypersensitivity. |
| • Tongue thrust: | Normal pattern is when the mature up-down controlled movement replaces the forward-backward movement. The abnormal patterns are not rhythmical. The tongue may protrude far beyond the mouth and the jaw is often open wide. The tongue may appear thick and bunched. |

Some children with disabilities experience feeding and drinking difficulties because the primitive reflexes are not replaced by mature reflexes. A child may have difficulty swallowing, may gag easily or experience abnormal tongue thrust. Therefore, nutrient intake is affected. Difficulties with sucking or being unable to suck may be the first indication in a child who later develops cerebral palsy (Werner, 1987). Feeding problems are often more

apparent than nutritional problems and can indicate the first signs of a disability permitting the possibility of early nutrition intervention if required (Dahl *et al*, 1993).

Tongue thrust swallowing in five patients with severe physical and mental disabilities was assessed by videofluoroscopy (Yokochi, 1996). The abnormal movements propelled the bolus of food so that it spilled to the sides of the mouth. Most of the bolus was not swallowed. The detailed observations in this study suggested intervention to facilitate feeding in children exhibiting tongue thrust should concentrate on both the limiting of tongue protrusion and the elevation of tongue and jaw control to permit firm molar contact, thus preventing spillage food. More studies like this are required to facilitate effective intervention.

Children with disabilities may require intervention in the process of learning to eat and drink for a number of different reasons. The most obvious are physical reasons that affect the control of movement in the structures involved with feeding, or unsuitable body positions affecting muscle tone and posture of the mouth and neck. Structural differences, for example those seen in cases of cleft lip and palette, can affect intake of food. A survey of children with cleft lip and palette conducted in the Philippines found 48% of the subjects as undernourished (Azares and Ignacio, 1980). There is a close relationship between feeding difficulties and oral communication disorders (Dahl *et al*, 1993; Thommessen *et al*, 1991). Some children with disabilities experience problems of hypersensitivity that leads to defensive actions upon a touch of the face. In contrast, other children experience hyposensitivity and show little reaction when food is near the mouth. Medical interventions with drugs may also affect appetite and the process of digestion (The Children's Trust, Care Assistants Training Manual, 1996).

Feeding and drinking difficulties are not all a direct consequence of the impairment or health condition. Nutritional status is also dependent upon the environmental interactions. In the case of a child with a disability, the role of the carer and the social environment may also contribute to difficulties [Figures 1.4 and 1.5]. Behavioural problems can compound any physical problems, thus, affecting intake (Richardson, 1988). The process of eating and drinking is based on learnt actions and experiences. A child who has had unhappy

experiences with feeding is less likely to want to eat. In addition, the immediate environment at meal times will influence children with a high propensity to distraction. A lack of communication between carer and child can also aggravate any feeding and drinking difficulties.

Feeding problems may have consequences for the overall carer-child relationship (Thommessen *et al*, 1991). Reilly and Skuse (1992) investigated the characteristics and management of feeding problems of young children with cerebral palsy, (with a range of severity) in the UK. Mealtime observations and interviews with the carers were conducted. Twelve cases were assessed and a second group of subjects served as controls. A lack of verbal communication was observed between the carer and children with cerebral palsy. Eight of the carers did not enjoy mealtimes and six carers experienced difficulties. The time factor was also identified as an important issue. Eight carers believed the child with cerebral palsy was a slow eater, which was significantly different ($P < 0.01$) than the control children. Knowledge of dealing with feeding difficulties was observed and consequently, the diets were restricted for children with cerebral palsy. Breast-feeding was also stopped earlier, (by 9 weeks for half of the children with cerebral palsy). The global promotion of breast-feeding for the provision of a good health status is growing. Therefore, in cases of difficulty early intervention would be beneficial to prevent ill health and poor nutrition. Carers felt under stress and nine carers expressed concern regarding the child's growth and nutrition.

Johnson and Deitz (1985) reported that feeding children with cerebral palsy can take up to 15 times longer than for other children, which is highly stressful for the carer. However, in a second study, Reilly and Skuse (1992) suggested that in some situations it was the perception of time spent on feeding rather than actual time spent that was stressful. Video recordings of mealtimes were compared to carer reports, which showed not as long time was spent on feeding as perceived. Parental adjustments to the needs of a child with disabilities are necessary in many situations. An observational study in the UK on seven children with severe cerebral palsy (aged 2-16 years) with weight matched controls also identified the time factor as a cause for concern (Gisel and Patrick, 1988). Children with cerebral palsy took 2-12 times longer to chew and swallow pureed food and 1-15 times longer for solid foods.

Despite, the importance of environmental interaction with respect to nutrition, there is little research exploring carers' role and feelings. There is plenty of anecdotal information on carers' concerns regarding time issues and other environmental factors, but no large-scale study. Currently, research is in progress at the Institute of Child Health, London (Craig *et al*, 2000) exploring attitudes pre and post- gastrostomy intervention.

Understanding, the role of nutrients and the process of eating and drinking permits the exploration of interventions when feeding difficulties or growth faltering are observed (Warner, 1981). Without intervention, the consequences include increased risk of entering the dietary intake/disease cycle and further impairment. Undernutrition in children with complex disabilities can lead to poor circulation, weaker muscles and an increased risk of aspiration and pneumonia. In contrast, obesity can result in further curvature on the spine and an increased risk of cardiac problems. For the carer, a dependent child becomes more difficult to manage for everyday tasks, (e.g. lifting) (Bax, 1993). An inadequate diet combined with poor feeding practices will limit the opportunity for cognitive, language and social development. Consequently, opportunities for community participation will be reduced, creating an environment of further disablement for the individual.

Figure 1.4. Environmental interactions and other influences for the child during meal times (Yousafzai: Disability and Impairment Course, Centre for International Child Health, London, 2000).

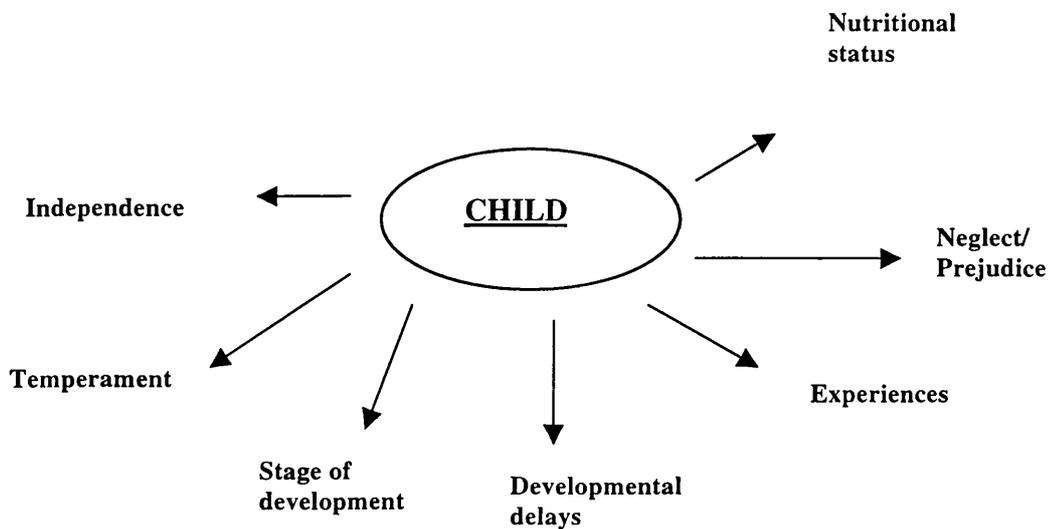
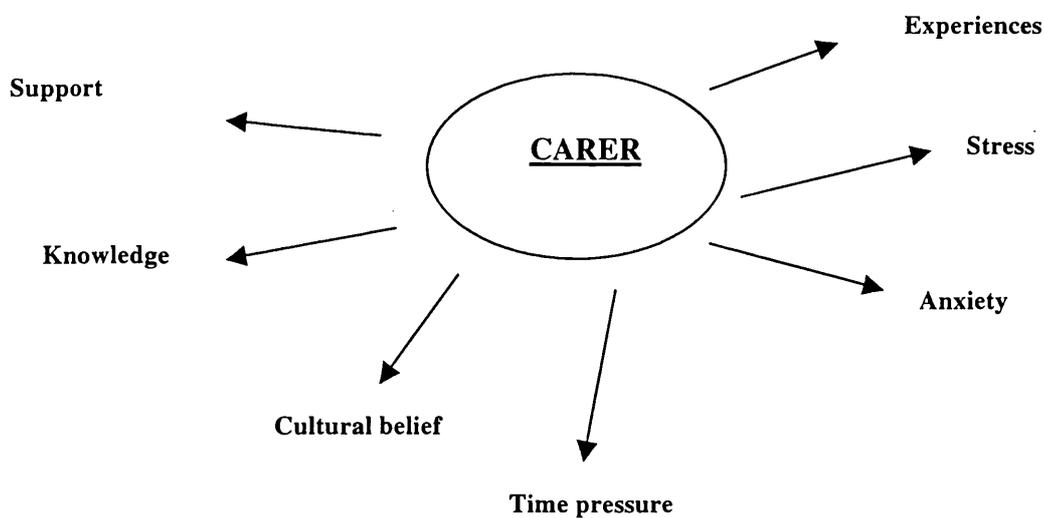


Figure 1.5. Environmental interactions and other influences for the carer during meal times (Yousafzai: Disability and Impairment Course, Centre for International Child Health, London, 2000).



Documented Evidence Suggesting Children with Disabilities are at Risk from a Poorer Nutritional Status

It should follow that with the present knowledge of health conditions and feeding difficulties, which could contribute to nutritional inadequacies and consequent problems that the nutritional vulnerabilities for children with disabilities are reduced. However, the limited data available indicates both that children with disabilities are at risk from poor nutritional status, and that present research does not provide sufficient information for this field.

Bax, in an editorial (1993), stated that in any surveys of people with disabilities, nutritional problems stand out. In a clinical study conducted in the UK by Thomas *et al* (1989), 40% of the physically impaired young adults assessed were either obese or thin. One in ten of the sample were rated as emaciated. Obesity was observed in 20% of the sample with a diagnosis of spina bifida. Obesity was also a common feature in wheel chair bound individuals with cerebral palsy; however, 16% of the cerebral palsy cases were identified as emaciated. In part, Bax felt the nutritional problems are ignored by clinicians because poor growth is an expected normality of a given health condition. For example, short stature is associated with Rett syndrome.

Obesity is associated with Prader-Willi syndrome and nutritional management is often ignored. In the first two years of life, poor weight gain and feeding difficulties are observed. Subsequently, there is mental impairment and then rapid weight gain. Morgan and Rolles (1984) conducted a longitudinal case study in the UK of an infant with Prader-Willi syndrome, investigating nutritional status and growth. The primary source of food at this time was breast milk. The child's body weight remained below the third centile of reference growth charts and continued in a downward trend over a 6-month period. Therefore, there was poor physical development and poor feeding exacerbated the situation.

In a prospective study, Willig *et al* (1993) recorded anthropometric data of 252 patients with Duchenne Muscular Dystrophy (DMD) in order to describe the progress of the health condition. DMD is an inherited progressive muscular disorder affecting males, in which

obesity can occur at the time of ambulation loss. It is also possible that undernutrition can increase muscle wasting, which may in part contribute to a loss of feeding independence. The theoretical 10th centile of weight for age emerging from the study showed weight stabilised between 23 and 27kg for most boys around 13 years of age. This was approximately at the same time of increased impairments including greater difficulties with self-feeding and swallowing.

Distinct feeding behaviours contributing to nutritional status are commonly observed in people with mental impairments. A few research papers have looked at particular case studies regarding specific eating disorders like pica, (the continuous eating of non-food items that has been associated with iron deficiency (Federman *et al.*, 1997)). O'Brien and Whitehouse (1990) reported feeding behaviours among 48 adults with different moderate to severe mental disabilities. The results from carer interviews identified that the adults with autism persistently sought out food throughout the day significantly more ($P < 0.05$) than the group with no disorder. No nutritional studies on children with autism or other specific mental disabilities can be found. The study did not correlate the feeding practices findings with measures of nutritional status.

Feeding practices and nutritional status assessment surveys have been conducted in Norway by Thommessen *et al* (1991a, b). 221 children, aged between 1-16 years with mixed disabilities and illnesses, (mild, moderate and severe), attending a specialist health centre were studied. The children were divided into seven groups by diagnosis: esophageal atresia, mental retardation (including Down syndrome, Rett syndrome, Fragile X syndrome), cerebral palsy, deaf-blind, congenital heart disease, cystic fibrosis and epilepsy. Larger studies often have a problem with classifying disabilities in to appropriate groups, (and in some cases rare syndromes with specific aetiologies are included in larger groups). This point is particularly important for the reproducibility of results.

In the first study height or length, weight and feeding problems were assessed by staff at the clinic. Height for age deviated significantly ($P < 0.01$) from the norm, (based on Norwegian growth reference charts) for children with severe cerebral palsy, deaf-blindness and mental

retardation. Heights and weight were significantly lower ($P < 0.01$) among children with oral-motor dysfunction and impaired-self feeding, (mainly those in the mental retardation group and those with cerebral palsy), than those children without these problems. However, the anthropometric data must be interpreted with caution as the researchers acknowledge limitations in obtaining accurate height information.

In the second study, a cross-section of the subjects was also assessed for energy and nutrient intake by weighed food intake diaries kept over 4 consecutive days. Children with oral-motor dysfunction and impaired self-feeding ability had significantly lower ($P < 0.05$) energy intake than those without. These were mainly children in the mental retardation group, children with cerebral palsy and the four children in the deaf-blind group. No differences were identified in nutrient intake. However, detailed biochemical analysis of micronutrients was not carried out. Food diaries are a source of error and only provided limited quantitative information regarding nutrient intake (Gibson, 1990). Only a sub-set of diaries with accurate information was used in the analysis.

A third smaller study by Thommessen *et al* (1989) assessed nutrition and growth retardation in ten children (aged 8-23 years) with congenital deaf-blindness attending a special boarding school. Diet records, biochemical assessment and anthropometry was conducted. The children all received vitamin supplementation from the school. Seven of the children were faltering in growth. No anaemia or PEM was found. All the children had feeding difficulties and refused food more frequently than other children of a similar age group. Good feeding practices had not been developed; for example, there were delays in starting solid foods.

Other researchers have explored the nutritional status of people with visual impairment. A pilot study assessed body mass index (BMI) of 25 Canadian adults (Roebathan, 1999). Thirteen adults had a BMI greater than 27, which is associated with an increased risk of illness such as diabetes, heart disease and hypertension (Gibson, 1990). No statistical analysis was performed on the data set. People with visual impairments may have mobility difficulties affecting their nutritional status. In a small study in Uganda, visually impaired children in a special school self-reported lower activity levels than their non-disabled peers. Visually

impaired children living at home self-reported fewer high-energy activities than their siblings (Harknett, 1998). However, the preliminary data from both studies does suggest the necessity for further work on nutritional assessment among visually impaired populations.

An overweight tendency was also seen in the results of a study conducted by Suzuki *et al* (1991). Nutritional status in relation to physical activity was studied among 2222 students in special schools in Tokyo, Japan. Students were classified as mentally retarded, deaf, blind or physically handicapped. Detailed anthropometric and activity measurements (using a pedometer) were made and feeding practices were assessed. For each group, the majority of students were within the normal ranges, (compared to Japanese reference charts) for weight. Deviations from the norm tended to be >2 standard deviations (SD) above the normal weight range rather than below. The overweight tendency was particularly noted in the physically handicapped group and the group classified as mentally retarded. A negative correlation was observed between level of activity and percentage of body fat among females with mental retardation. The researchers recommended a review of dietary guidelines and physical education provided in special schools in Tokyo. Other researchers have noted sedentary lifestyles and overeating among adults with mental disabilities to contribute to weight gain (e.g. Jackson and Thorbecke, 1982). Activity levels should be included in future nutritional studies of people with disabilities.

A lot of research is documented on the potential benefits of nutritional therapy for the management of Down syndrome (Ani *et al*, 2000; Wynn, 1984). Some attention is given towards obesity in children with Down syndrome. It has been reported that children with Down syndrome are shorter and heavier than other children of similar ages (e.g. Cronk *et al*, 1988; Thelander *et al*, 1966). Difficulties in feeding can occur because of impairments in the oral cavity.

Luke *et al* (1994) investigated energy expenditure in 13 children (aged 5-11 years) with Down syndrome and 10 controls. The children were selected to represent a range of body sizes. Energy expenditure was measured using the doubly labelled water technique. However, the study raised questions about the appropriateness of this technique for assessing young

children who cannot often remain still for the resting energy expenditure assessment. The results showed that the resting energy metabolic rate was significantly lower ($P < 0.01$) compared to normal children, which may in part pre-dispose children with Down syndrome to early weight gain.

Calvert *et al* (1976) in the USA looked at feeding practices of 40 children with Down syndrome. 2-day food records estimated dietary intakes. The study does not provide detailed methodology. The results were variable and were compared to recommended dietary allowances (RDA). RDAs are variable from country to country. The RDAs only provide an indication of the average recommended intake over a reasonable period of time and do not take in to consideration possible interactions with other nutrient in the body (Gibson, 1990). Calvert *et al* found the energy intake was below the RDA for more than half the study sample. More interestingly were the reports of carers using food to modify behaviour in their child, for example, as discipline or to keep the child happy. Little work has been conducted in this area with respect to disability.

No micronutrient data could be found to review in this section. Table 1.6 summarises the commonly reported nutritional problems in selected disabilities and syndromes (American Dietetic Association, 1992).

Table 1.6. Frequently reported nutrition problems and factors contributing to nutritional risks in selected developmental disabilities

Syndrome/ disability	Altered growth rate/growth retardation	Altered energy need	Altered nutrient needs/deficiency	Constipation/ diarrhoea	Feeding problems	Others
Cerebral palsy	✓	✓	✓	✓	✓	poor appetite, orthopedic problems
Epilepsy			✓	✓		dilantin-induced hyperplasia of gums
DMD	✓	✓		✓	✓	
Down syndrome	✓	✓	✓	✓	✓	gum disease
Prader-Willi syndrome	✓	✓			✓	
Mental retardation	✓	✓		✓	✓	drug-nutrient interaction, pica
Autism					✓	drug-nutrient interaction, pica

The largest literature on nutrition and disability is for children with cerebral palsy. Cerebral palsy is not a single condition. The term refers to a disorder of movement and posture due to damage or failure in the development of part of the brain. It is a non-progressive disorder, and severity and symptoms vary widely among individuals with cerebral palsy. Symptoms can include visual impairments, hearing impairments, learning disabilities and difficulties with perception. There are three main types of classification: 1) Spasticity- disordered control of movement; 2) Athetosis- frequent involuntary movements; and 3) Ataxia- loss of control of voluntary movements. The condition can be described as quadriplegic (affecting all four limbs), diplegic (affecting the lower or upper half of the body), or hemiplegic (affecting either the right or left side of the body). Occurrence of cerebral palsy is common at birth, (due to starvation of oxygen to the brain). Good pre-natal and perinatal care is essential in the prevention or early intervention of cerebral palsy.

Cerebral palsy occurs in every 2 per 1000 live births (Polnay and Hull, 1993). The prevalence figures quoted in the literature range from 1-4 per 1000 live births (e.g. Nelson and Ellenburg,

1978). The numbers will vary depending on the population, however, it is a globally common condition. In paediatric clinics in Africa, cerebral palsy accounts for 40 to 50% of referrals (Nottidge and Okogbo, 1991).

Children with cerebral palsy have been reported as being lighter and shorter than their peers since the 1960s, (Tobis *et al*, 1961). In more recent times, a study by Krick *et al* (1996) based on 360 American children with quadriplegic cerebral palsy found they had distinctly lower measures of nutritional indices, (at least 1.5 Z scores lower in weight for age, height for age and weight for height), compared to the National Centre for Health Statistic (NCHS) norms. It should be noted that half of the children were towards the severe end of disability and were either partially or wholly tube fed, i.e. receiving intensive nutritional interventions.

Feeding problems have been reported for between 40-50% of children with cerebral palsy, of which severe problems were reported in 85% of quadriplegic cases (Trier and Thomas, 1998). In a study of pre-school children with cerebral palsy, feeding problems were found in 90% of the sample and 46% were classified as having severe problems (Reilly and Skuse, 1994). Oral-motor dysfunction is one of the main causes of feeding problems, for example poor head control, abnormal tongue thrust, poor swallow reflexes manifesting as drooling, gagging and loss of food. Krick and van Duyn (1984) showed a clear correlation between the severity of cerebral palsy and dysphagia and impairments of the oral-motor functions.

Gastrointestinal symptoms often present in cases of cerebral palsy (del Giudice, 1997). Vomiting is associated in 75% of cases with gastrointestinal reflux (Trier and Thomas, 1998). Other symptoms include delayed gastric emptying and chronic constipation (Staiano *et al*, 1991; 1994). Such symptoms cause discomfort and affect appetite. More research is required to understand the correlation between gastrointestinal dysfunction in cerebral palsy and lesions of the central nervous system (del Giudice, 1997).

Consequently, feeding problems can contribute to undernutrition identified in studies such as Thommessen *et al* (1991a, b, c). In the past studies were conducted to determine whether the growth retardation observed in children with cerebral palsy was as a consequence of

neurological factors or poor nutrition. However, most researchers are now in agreement that nutritional factors play an important role in the growth of children with cerebral palsy in addition to their overall well-being (e.g. Shapiro *et al*, 1986; Stallings *et al*, 1993; Hals *et al*, 1996).

A retrospective review of 19 children (aged 5-168 months) supported the view that nutritional factors do have a role in growth failure (Shapiro *et al*, 1986). Detailed medical records were reviewed before and after gastrostomy surgery. Occupational therapists' assessments found 17 of the children had oral-motor dysfunction and 15 of the children were showing signs of failure to thrive, (weight for height less than the 3rd centile of reference growth charts). The aim of the gastrostomy intervention was to provide improved nutritional intakes. Pre-intervention the mean weight for length Z score was -2.71 and post-intervention this improved to -1.18. On average children improved by 1.5 standard deviation scores, (nearer the 50th percentile of growth charts). It should be noted the cases reviewed in this study were profound and are not representative of the general population with cerebral palsy.

A question often raised among researchers in this field is whether undernutrition is a consequence of low energy intake or increased energy requirements, (due to involuntary muscular movement in spasticity)? Stallings *et al* (1996), addressed this issue and examined energy expenditure of children and adolescents with severe quadriplegic cerebral palsy. 61 children with cerebral palsy (aged between 2-18 years) attending specialist centres and 37 controls of similar age and sex had resting energy expenditure (REE) (assessed by open circuit indirect calorimetry), and total energy expenditure (TEE) (assessed by doubly labelled water) measured. The TEE was significantly lower ($P < 0.05$) for the cases compared to the control group. The ratio of TEE:REE was significantly different between the two groups indicating the non-basal energy expenditure for children with cerebral palsy children (1.23) were less than for the control group (1.57). The researchers concluded that part of the nutrition related growth failure was likely to be because of inadequate energy intake, and not increased energy requirement, in severe quadriplegic cerebral palsy.

Nutritional indicators in relation to measures of growth were investigated in two separate studies by Stallings *et al* (1993a, b). The first clinical study sample comprised 142 children with severe quadriplegic cerebral palsy. The second study group comprised 154 children with less severe disability; either diplegic (n=96) or hemiplegic (n=58) cerebral palsy, (there is less documented work in this area). Children were aged between 2-18 years. In both studies linear growth (upper arm length and lower leg length), body fat and muscle area, ambulatory status, oral-motor status and cognitive ability were measured.

Two-stage step-wise multiple regression analysis showed significant correlations ($P<0.01$) between muscle area and linear growth for all children with quadriplegic cerebral palsy. However, significant associations ($P<0.05$) between body fat and linear growth were only observed in children less than 8 years of age. Linear growth provides a useful measure of nutritional status in severe cases. Weight was not taken because of practical difficulties.

For diplegic and hemiplegic cases significant correlations ($P<0.01$) were observed between weight and nutritional indicators of body fat and muscle area in the second study. A significant correlation ($P<0.05$) was also seen for linear growth and nutritional indicators of body fat and muscle area. About 30% of the sample were identified as undernourished based on body weight and body fat indicators. Oral-motor problems were significantly more prevalent ($P<0.01$) among the hemiplegic group than the diplegic group, although no significant nutritional differences were found between the two groups. Overall, most of the group (63%) had no feeding impairment as defined by oral-motor difficulties. Undernutrition in diplegic and hemiplegic is a problem as well as in quadriplegic cases of cerebral palsy.

The nutritional problems of those with diplegic or hemiplegic cerebral palsy were found in study of feeding and nutritional problems of children with cerebral palsy and myelomeningocele conducted by Dahl and Gebre-Medhin (1993). A sample of 30 children with cerebral palsy, (no quadriplegic cases) or myelomeningocele living in a special home had feeding problems assessed and anthropometry measured. This study did identify feeding problems in all of the children, (assessing more than oral-motor skills). A significant association ($P<0.001$) was identified between poor oral communication and feeding problems

for the whole group. Weight for age, height for age and weight for height Z scores were compared to the NCHS reference, (however, concerns over height accuracy are raised). Children with diplegic cerebral palsy had significantly low scores in all three indices, while children with hemiplegic cerebral palsy had near normal scores. More feeding problems were observed for diplegic cases. Therefore, the study indicates more attention is needed for children with diplegic cerebral palsy. A larger sample size with more representative cases is required to confirm this.

The association between feeding problems and growth is further confirmed by Thommessen *et al* (1991a). Cross-sectional analyses of 22 children with cerebral palsy and feeding problems had significantly lower ($P<0.05$) height for age, weight for age, skinfold thicknesses and upper arm circumferences than 20 children with cerebral palsy, but without feeding problems. Significant associations ($P<0.01$) between undernutrition (based on anthropometry) and feeding problems were reported in a study of 35 children with moderate-severe cerebral palsy (Dahl *et al*, 1996). The researchers reported 7 height measurements were discarded because of unreliability, which has been noted as a common problem in several studies.

Rampage *et al* (1996) raises the important issue for clinicians to consider not only the calorific intake and growth outcome, but also undernutrition with respect to micronutrient intake. The biochemical analysis of ten patients with severe cerebral palsy indicated deficiencies of selenium, zinc and vitamin D (without rickets). This is particularly important when considering the nutrient components for gastrostomy feeds (Nutrition Committee, Canadian Paediatric Society, 1994). Hals *et al* (1996) recognised the requirement of improved micronutrient intake and conducted a small intervention study on 13 institutionalised children with severe cerebral palsy. The children were supplemented with high-energy formula and micronutrients with mixed results. Two of the children who could not participate in the intervention because of late entry in to the study were supplemented with infant formula, despite being far older. However, infant feeds are sometimes recommended because of high ratios of nutrients to energy (Canadian Paediatric Society, 1994). The study notes the complex interactions between motor encephalopathy and calorific/micronutrient needs. It raises questions about the value of reference norms.

However, not all cerebral palsy cases reflect severe disability or severe feeding difficulties. Independent food preference was surveyed for boys with cerebral palsy attending a special boarding school and compared to boys in three private schools and one state school in the UK (Nicholson and Eddy, 1967). The sample size is not clear from the report. Children answered structured questionnaires based on the likes and dislikes of groups of food. The key finding was the tendency to change from sweet to savoury preferences occurred around 15 years of age for the control boys. For the boys with cerebral palsy, the preference for sweet food remained at 15 years of age and it was more similar to preferences displayed by boys 3-4 years younger. It is not known whether this has any impact on nutritional status or whether this finding would be similar for females.

In summary, the majority of the studies described comprise samples of very severely impaired subjects and some with rare syndromes, which become disabling. Subjects are commonly selected from specialised clinical settings and the data is based mainly on clinical assessments with unclear descriptions of control groups. Clear mechanisms for nutritional problems, physiological and environmental interactions, and the disability are yet to be understood. The researchers are in agreement that undernutrition exists in populations of children with disabilities and those feeding problems do contribute to poor growth. Nutrition of children with developmental disabilities in particular is a cause for concern (American Dietetic Association, 1981). However, more work is required to survey the nutritional status of more representative populations, although it is acknowledged that it is very difficult to conduct large surveys of people with disabilities for such studies. Participation and motivation is often successful with convenience samples. Further work on micronutrients is needed. Clarification of guidelines are required on assessment techniques and references; this issue is raised in several studies. There is also a lack of work addressing other topics, (e.g. carers'/peers' attitudes, food preferences), which can interact with nutritional status, with some exceptions such as work by Reilly and Skuse (1992). Large intervention trials are also needed to test the effectiveness of possible solutions.

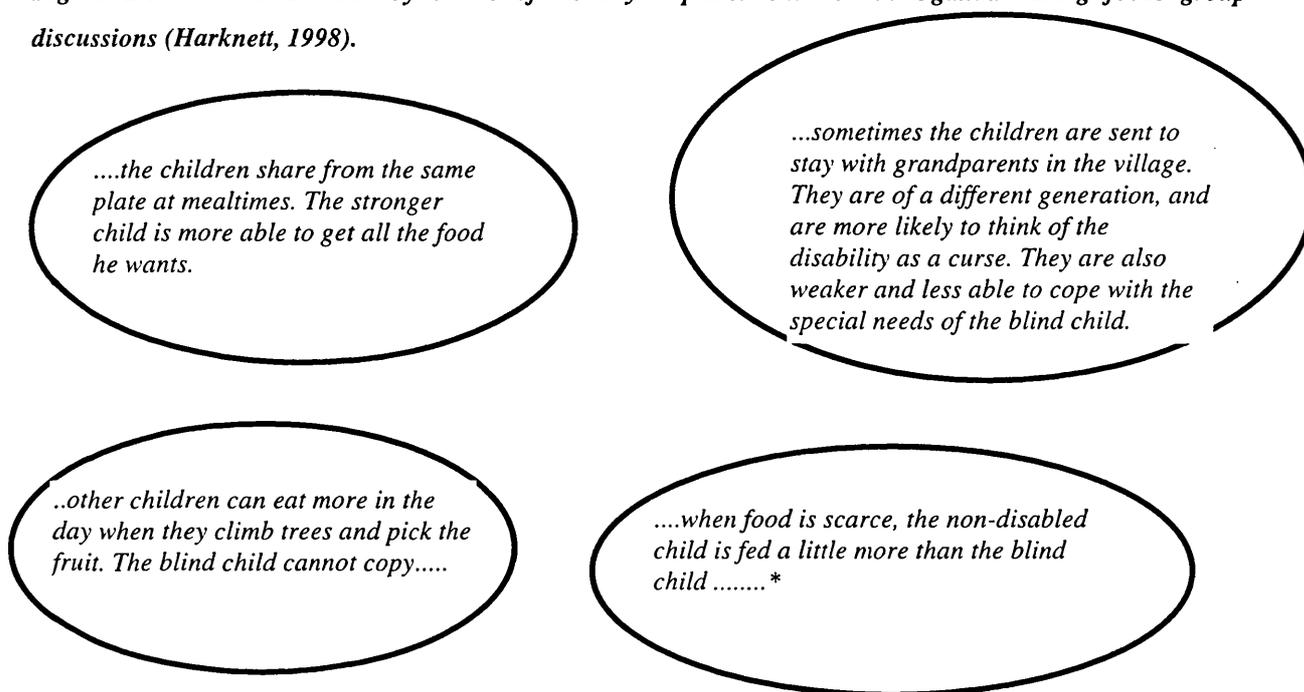
Studies from Developing Countries

The majority of children with disabilities are living in the developing world. The findings of nutrition studies conducted in Europe and North America are relevant for children everywhere. However, there are many specific considerations for those living in the majority world. For example, because of scarce resources many children will have limited access to specialised clinics and rehabilitation centres. In countries where malnutrition prevalence is high among the general population, the special nutritional needs of the child with a disability may not draw sufficient attention. The expensive intervention approaches may not be appropriate for children from very poor backgrounds. An understanding of the different societal factors is required.

A search of the literature in disability is scattered with anecdotal comments regarding neglect and poor nutritional status of the child with a disability. Children with disabilities living in poverty may be at risk of inadequate nutritional status due to financial constraints or social beliefs (Mallory *et al*, 1993). Focus group discussions with carers of visually impaired children in Uganda raised several points of interest (Harknett, 1998) [Figure 1.6].

Cultural beliefs must be understood. There may be factors such as prejudice involved, or it may simply be a lack of knowledge or understanding of the disability. For example, a cross-sectional screening survey of disabilities in rural Thailand (Pongrapei *et al*, 1996), found delays in health seeking behaviour, with carers citing reasons such as the belief that the disability was a temporary illness, and expecting the child would get better. King and Burgess (1993) discuss helping families in poor communities with nutrition for the sick child. A disabled child can be thought of as ill thus, inadequate nutrition continues for a long time. Where no intervention has occurred for the early development of feeding skills, an older child may still continue to be fed like an infant leading to inappropriate meals, and nutrient deficiencies for the growing child.

Figure 1.6. Comments made by carers of visually impaired children in Uganda during focus group discussions (Harknett, 1998).



*Note: *- one carer in the research discussions only made this comment.*

The DIFD report on “Disability, Poverty and Development” (2000), also makes several references to the nutritional neglect of the disabled child. Harris-White (1999) estimated mortality rates for the disabled child may be as high as 80% in the same countries where the mortality rates for the under fives has decreased considerably. Figure 1.1 showed a poverty and disability vicious cycle. Poverty is also a cause of malnutrition, (e.g. inadequate sanitation, lack of household food security). Therefore, it may be hypothesised that the child with disabilities is likely to face an increased impact from the consequences of poverty, malnutrition and disability. In communities where poverty itself is disabling, the nutritional needs of disabled children may not be a high priority issue to address.

A team in Bangladesh and the Wolfson Centre (Institute of Child Health, London) followed a group of children (under 5 years) with cerebral palsy as part of a larger intervention study to investigate service provision for children with special needs in urban and rural areas (Khan *et al*, 1998; Mobarak *et al*, 2000; McConachie *et al*, 2000). Mortality over the 3 year study period was investigated. Eight children died (6 from the rural area and 2 from the urban area)

from the 92 monitored. Although factors such as infection and drug interaction were involved, it was noted that the children who died were among the most severely disabled in the group and most were severely malnourished. Nutrition and primary health care should serve as important components of rehabilitation services. The study also addressed stress experienced by mothers. 38 of the 91 mothers were considered at risk of psychiatric morbidity with issues such as the burden of caring for a disabled child being a major cause. This is an example of an environmental care factor that could contribute to the nutritional status of the child, and is relevant to all families with a child with disabilities.

Through a literature search only 6 studies were found, which focused on nutrition in children with disabilities from developing countries. The studies are summarised in tables 1.7.1-1.7.4. Three of the studies are from Nigeria, one from India, one from Lebanon, and one from the Philippines. They cover both urban and rural areas. In each study, indices of nutritional status by anthropometry indicate signs of malnutrition among the children with disabilities.

Four of the studies drew the disabled population from special schools or institutions where one would expect more attention to the special needs of the child. However, this does not appear to be the case with respect to nutrition. Ojofeitimi (1983) reported the lack of health professionals visiting the children in the special education class to follow up on basic care needs. Shaar *et al* (1994) reported the children within the institution appear to be more at risk of malnutrition. This is partly in agreement with the study discussed earlier by Hals *et al* (1996), where neurological impairments combined with institutionalism can have a detrimental effect upon growth and nutritional status. The current trend is to move away from institutional care and towards community care for people with disabilities. This move is beneficial for a number of reasons, including social integration for the benefit of the individual and his/her community.

None of the studies reported any gender differences in the nutritional status of the children with disabilities. Shaar *et al* (1994) reported more boys with disabilities participated because fewer girls were present in the institutions. The researchers reported this may be due to a cultural taboo of sending girls away from the home.

In studies by Alakija (1998) and Shaar *et al* (1994) , control groups came from different SES backgrounds. The children with disabilities came from lower income families and were more comparable to the control groups from the lower SES. Therefore, the greater significant differences shown between the groups with disabilities and the controls from a higher SES may not be important. In studies by Tompsett *et al* (1999), Socrates *et al* (2000) and Pai *et al* (2001) controls were selected from the same neighbourhoods. Pai *et al* (2001) did record information on SES such as housing type and no differences were seen between control and case families. It is thought, families with a disabled child may be poorer; for example, Pongprapei *et al*, (1996) in Thailand found people sought out a lot of expensive medical treatment in the hope of finding a cure for the disability. However, none of the studies were designed to test this hypothesis and so no conclusions can be drawn. However, Tompsett *et al* (1999) did suggest that there were no resources in the rural area for money to be spent.

Studies by Tompsett *et al* (1999), Socrates *et al* (2000) and Pai *et al* (2001) also used sibling controls. No differences were found between the neighbour controls and siblings', suggesting that disability in the family does not effect the nutritional status of the siblings.

Mainly the studies focused on children with sensory or mental impairments. Socrates *et al* (2000) looked specifically at children with cerebral palsy. The study confirmed the association between feeding difficulties assessed by health care professionals and inadequate nutrition found in the studies discussed earlier, (e.g. Krick *et al*, 1996; 1984). Studies by Tompsett *et al* (1999) and Pai *et al* (2001) looked at mixed disabilities. Tompsett *et al* (1999) identified the main inadequacies were among children with neurological disabilities.

Apart from haemoglobin as an indicator of iron-deficiency anaemia no other micronutrients were studied. Pai *et al* (2001) however did explore dietary habits using a food frequency table and found meat, fish and dairy products were more rarely consumed among children in families with a disability.

Nutritional status was assessed using anthropometry. Much discussion is devoted to suitable means of measuring height accurately in children with kyphosis or scoliosis, or weight in children who are heavy and not mobile. Studies by Tompsett *et al* (1999) and Pai *et al* (2001) suggested alternative measures of armspan (distance between the longest tip of one arm to the other) and halfspan (distance between the tip of the middle finger of one arm to the mid-sternal notch) as suitable predictors of height. A slight criticism of full armspan is difficulties in children with spasticity in both arms, indeed it was not suitable for 2 of the 31 children in the study conducted by Socrates *et al* (2000). These issues are discussed in more detail in the section on study limitations.

There were no intervention studies. However, before an intervention study is attempted much more qualitative information is required to understand possible reasons for the nutritional differences observed. It is not sufficient to recognise a difference in nutritional status without exploring all the possible reasons to contribute to the differences, (both the external environmental factors, and the feeding problems).

Table 1. 7.1. A summary of the nutrition and disability studies from developing countries.

Researcher and Country	Sample Size	Design	Outcome Measures	Key Findings
1. Ojofeitimi, 1983 Nigeria (Urban)	24 children (7-15y) <ul style="list-style-type: none"> • 11 deaf-dumb • 13 mentally retarded 	Nutrition survey in a special education class.	<ul style="list-style-type: none"> • Wt/Ht² & MUAC/Ht² to classify degree of malnutrition. • Anaemia screening by conjunctival examination. • Observations of personal cleanliness. 	<ul style="list-style-type: none"> • 13 showed signs of mild-severe malnutrition by Wt/Ht² (<0.00156). • 14 showed signs of mild-severe malnutrition by MUAC/Ht² (<0.1350). • 15 children suspected of anaemia. • 3/4 signs of poor personal cleanliness.
2. Alakija, 1988 Nigeria (Urban)	School children (6-12y) <ul style="list-style-type: none"> • 98 with disabilities (deaf, blind or mentally impaired) • 2597 non-disabled (lower SES) • 560 non-disabled (higher SES) 	Cross-sectional	Body Mass Index (BMI) to assess nutritional status (weight/height ² X 100)	<ul style="list-style-type: none"> • Mean results in each age group showed mild malnutrition in all children with disabilities (0.13-0.15). • Low SES < 10y showed mild malnutrition. No malnutrition in high SES group.

Note: Key- Ht= height, Wt= weight, Hb= haemoglobin.

Table 1.7.2. A summary of the nutrition and disability studies from developing countries.

Researcher and Country	Sample Size	Design	Outcome Measures	Key Findings
3. Shaar <i>et al</i> , 1994 Lebanon (Urban)	Subject 6-10y <ul style="list-style-type: none"> • 185 sensory impaired (living in an institution/special day school) • 185 randomly matched (sex, age) controls from public school. • 185 randomly matched (sex, age) controls from private school. 	Group-Control	<ul style="list-style-type: none"> • Ht/age and wt/age converted to Z scores using NCHS reference.* • Aggressive behaviour scores **. • SES information. 	<ul style="list-style-type: none"> • Children with disabilities similar SES to controls from public schools ($P>0.05$). • Disabled children mean Z score in ht/age significantly lower than public school controls at 6-10y and in all ages with private school controls ($P<0.05$). • Wt/age mean Z score significantly lower than public school controls at 10y and in all ages with private school controls ($P<0.05$). • 34.6% disabled, 16.8% public school controls & 4.3% private school controls in lower centile (<10th) ranges of NCHS references. • Living in an institution as main risk for low wt and ht by multiple linear regression.

Note: Key- Ht= height, Wt= weight, Hb= haemoglobin.

**NCHS reference data from USA is felt to be suitable for international data of normal growth (Kow *et al*, 1991).*

*** Agressive behaviour score by Conner's Teaching Rating Scale.*

Table 1.7.3. A summary of the nutrition and disability studies from developing countries.

Researcher and Country	Sample Size	Design	Outcome Measures	Key Findings
4. Tompsett <i>et al</i> , 1999 Nigeria (Rural and Urban)	<ul style="list-style-type: none"> • 112 children with mixed disabilities (<10y). • 87 sibling controls (nearest in age). • 112 neighbour controls (matched age and sex). 	Cross-sectional survey.	<ul style="list-style-type: none"> • Anthropometry: converted to Z scores using NCHS reference. * Halfspan as a proxy for height. • Haemoglobin 	<ul style="list-style-type: none"> • Disabled subjects mean ht/age and wt/age significantly lower (P<0.05) than control group. • Mean Hb higher in disabled and siblings (107g/l) than neighbour controls (101g/l) (P<0.05). • Halfspan correlated well with heights in controls ($r^2=0.89$).
5. Socrates <i>et al</i> , (2000) Philippines (Rural)	31 children with cerebral palsy, 20 nearest in age sibling controls & 64 neighbour controls (matched by age, sex). 2-10y.	Group-control.	<ul style="list-style-type: none"> • Anthropometry: converted to Z scores using NCHS reference. * Armspan as a proxy for height. • Severity of disability • Severity of feeding difficulty 	<ul style="list-style-type: none"> • Disabled cases significantly lower mean values in ht/age, wt/age & wt/ht (P<0.05) than all controls. Prevalence for moderate to severe malnutrition was greater for disabled case group. • Wt/age significantly lower (P<0.05) in severe feeding group than no/moderate. • Armspan correlated well with heights in controls ($r^2=0.985$).

Note: Key- Ht= height, Wt= weight, Hb= haemoglobin.

***NCHS reference data from USA is felt to be suitable for international data of normal growth (Kow *et al*, 1991).**

Table 1.7.4. A summary of the nutrition and disability studies from developing countries.

Researcher and Country	Sample Size	Design	Outcome Measures	Key Findings
6. Pai <i>et al</i> , (2001) India (Urban slum)	Children 2-10y <ul style="list-style-type: none"> • 50 families with disabled child (and sibling). Mixed disabilities. • 50 control families (no disability present). 	Group-control study using an opportunistic sample from an integrated pre-school in slum. An exploratory pilot study.	<ul style="list-style-type: none"> • Anthropometry: converted to Z scores using NCHS reference. * • Hb • SES • Food frequency 	<ul style="list-style-type: none"> • Ht/age significantly lower ($P < 0.05$) for disabled children compared to controls. Wt/age lowest mean of -2.78 compared to siblings (-2.53) & neighbours (-2.37). • Disabled children lowest Hb (103g/l). Sibling and neighbour controls mean was each 106g/l. • Children in families with disability more rarely consume meat, fish and dairy products.

Note: Key- Ht= height, Wt= weight, Hb= haemoglobin.

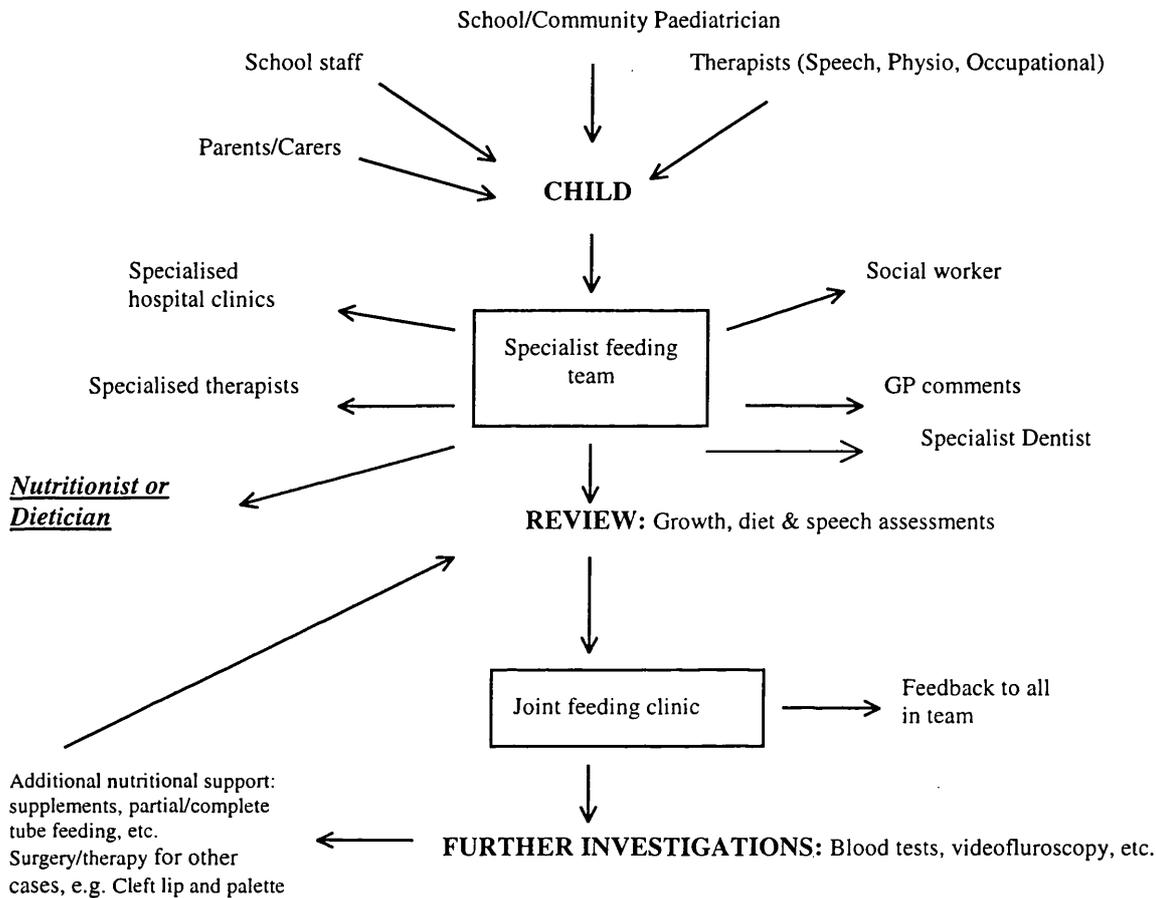
**NCHS reference data from USA is felt to be suitable for international data of normal growth (Kow *et al*, 1991).*

Appropriate Interventions to Attain the Goal of a Balanced Nutritional Status for Children with Disabilities

Intervention studies in the field of nutrition and disability are few. However, recommendations based on both observations by health professionals and various committees (e.g. The American Dietetic Association, The Nutrition Committee of the Canadian Paediatric Society) have suggested the predominantly descriptive studies documented. For children with a neuro-developmental disability, the nutrition management by a multidisciplinary team is recommended [Figure 1.7]. Ideally, feedback and good communication with the carers play a key role in the successful ability of the team to work towards improving the nutritional status. To facilitate the clinical assessments conducted by the multidisciplinary team, feeding assessment and/or nutrition schedules have been developed (e.g. Kenny *et al*, 1989; Wodarski, 1990). However, there is no current gold standard procedure. The protocol by Kenny *et al* (1989) was the first to be developed after rigorous statistical analysis.

In practice, the role of the dietician or clinical nutritionist is often ignored. However, the recognition of the importance of the nutritionist's involvement has been noted for a long time. In Wallace's review (1972), the active involvement of dieticians is recommended not only in specialised clinics, but also within the community where most children with disabilities will be seen (Wallace, 1972; Dufton-Gross, 1979). In the USA in 1979, the "Supplemented Security Insurance / Disabled Children's" legislation required nutrition as a major component of care and therapy (Caldwell, 1982). Attention towards the individual dietary needs of people with disabilities, with the involvement of a dietician, was noted in a study exploring an intensive nutritional rehabilitation programme for adults with severe disabilities in an institution. Often, in institutions a universal menu is given without consideration of individual needs, preferences, and independent choice (Hogan and Evers, 1997). Secondary problems as a result of eating habits such as frequent occurrence of dental caries, or poor oral hygiene in some physically impaired children led to suggestions of the need for specialised dentists as part of the multidisciplinary team (Webb, 1980).

Figure 1.7. Proposed scheme for assessment of feeding problems involving a multidisciplinary team (adapted from Trier and Thomas, 1998).



The specialised skills of a multidisciplinary team are not available to many children with disabilities, nor are they required in all situations, particularly the countries of the South. Basic interventions to overcome feeding and nutritional problems can be taught to the carer to facilitate the all round development of the child. For children with physical feeding difficulties specialised equipment is available (e.g. easy to grip cutlery and mugs, specialised seating) (Jones, 1978; Malcahy *et al*, 1988; Green *et al*, 1993). In children with mild disabilities, oral-motor skills should be maintained and improved. For example, exercises to facilitate swallowing and chewing have been developed (Winstock, 1994; Warner, 1981). In poor communities where access to specialised equipment is limited a collection of feeding and nutrition guidebooks have been developed as resources for the CHW and carer, (e.g. *Helping a child with eating and drinking difficulties*. Solo; Indonesia: CBR Development and

Training Center; *Feeding for the child with cerebral palsy*. The Indian Institute of Cerebral Palsy; *Disabled Village Children*, David Werner). Limited information on nutrition and primary health care factors other than feeding difficulties are included, which would be useful to the carer of the child with disabilities who may otherwise have little time or opportunity to receive such information. However, the effectiveness of such training manuals, predominantly found in the grey literature, has never been evaluated. Recently, a manual on early identification and intervention of childhood disabilities has been developed to train primary health care workers in low income communities which does include aspects of primary health care also (e.g. immunisation) (Wirz *et al*, 2000).

Nutrition supplementation is considered for children failing to thrive. The two formal intervention studies found in the literature both looked at nutrition supplementation (Hals *et al*. 1996; Ball *et al*. 1999). Ball *et al*. used a nutritionally complete food Nutrifil, (previously evaluated in malnourished populations), as an intervention among neurologically disabled children living in a Romanian orphanage. The supplemented group was compared to a non-supplemented group over eight months. Weight gain and improvements in weight for height were highly significant among the supplemented group ($P < 0.001$). Weight gain over the same period for the non-supplemented group was less significant. However, children were not assigned randomly to the two groups. The supplemented group was classified as mildly wasted at baseline and 10.2y mean age. In contrast, the non-supplemented group had normal weight for height range and 13.0y mean age. The study by Hals *et al* was also in an institution with severely disabled children. Micronutrient supplementation was tested. The results were variable on the 13 subjects with no clear benefits.

Oral feeding is the first option. However, when a child fails to thrive, tube feeding is considered an option, for example, in situations of extreme gastro-oesophageal reflux, required for additional nutritional support, or in cases of caustic burns to the oesophagus. The first method is a bolus feed, which is a replacement of a meal or a top up. The second method is continuous feeding via an enteral pump. Mixtures can include either be whole proteins or chemically defined products (peptides, amino acids). The content and balance of nutrients is debated extensively depending on the activity level, disability and energy requirements

because both underweight and overweight can be observed in children with cerebral palsy (Rampage *et al*, 1997; Hals *et al* 1996; Canadian Paediatric Society, 1994). The validity of RDAs is debatable here. In severe neurodevelopmental disabilities, often low energy intake is recommended because of reduced muscle mass and activity. The aim of tube feeding is to prevent malnutrition and improve the quality of life by increasing comfort and decreasing stress (Coldicutt, 1994). This can be a stressful decision for carers and child alike and the non-physiological or non-medical impacts have been under-studied at present (Craig, 2000; Langley, 1994).

Studies have investigated the medical advantages and disadvantages of gastrostomy surgery (e.g. van Calcar *et al*, 1989; Corwin *et al*, 1996). Corwin *et al* (1996) followed weight and linear growth changes in 75 subjects pre- and post surgery. Significant catch-up growth in children who were both orally and tube fed was observed ($P=0.03$), and in height for weight of non-ambulatory patients ($P=0.008$). However, this option is available for and relevant for only the minority of children with disabilities in the world.

Khan *et al* (1998), based on results from a mortality study in Bangladesh, recommended that community rehabilitation services include a nutrition component. The same team of researchers conducted a randomised, controlled trial of model services for young children with cerebral palsy. Outcome measures included maternal stress and knowledge, and changes in the child's adaptive skills. The study found, even among the minimal intervention control group, positive effects on maternal stress levels and knowledge (McConachie *et al*, 2000). In theory, nutrition components can be included in such programmes. Such programmes of support could also prove useful for carers in high income countries by providing an opportunity to discuss issues outside of the clinic environment.

Maternal knowledge has been identified as an important determinant of the child's nutritional status. In a study of childhood malnutrition and mother's nutrition related knowledge, attitudes and practices (KAP) in an Indian slum, a strong correlation was found between the nutritional status of the child and maternal education (Gupta *et al*, 1991). Important areas of

KAP identified were related to nutritional value of foods, immunisation, hygiene and diarrhoea.

Participation in nutrition and health programmes is complex and dependent upon many factors. Carmichael *et al* (1994) looked at determinants for a nutritional supplementation programme in Guatemala and identified factors such as distance to the programme from the home, family size and literacy of mother as important attendance determinants. An under fives' clinic in a slum area near Mumbai identified greater attendance to the community based model compared to the centrally located rehabilitation centre serving the same SES population (Kowli *et al*, 1984). Participation factors will vary in different communities and each culture must be understood.

For children with disabilities additional factors need to be considered. For example, a child who is not mobile, and can no longer be carried by the mother, is less likely to reach either a nutrition programme or other rehabilitation/education services, therefore increasing their isolation from the community. This is a prime example of an external environmental factor that can have an impact upon the nutritional status of the child and subsequent development and participation. Children with disabilities who can reach the programme are likely to participate with siblings. No formal nutrition programme specifically for children with disabilities or with a component to consider the special needs of some children with disabilities in poor communities can be found at present.

Current Limitations in Studies of Nutrition and Disability

There are several unresolved issues that require attention before informative guidelines for policy and management of nutrition in children with disabilities can be made with confidence.

Firstly, the descriptive process is discussed. The nutritional assessment process by which the nutritional status is determined is associated with distinct problems. In several progressive syndromes, which have disabling effects (e.g. DMD), the assessment is complicated by the interactions of the primary disease process. In children with moderate to severe neurological

disabilities (e.g. cerebral palsy), more information of the changes in the physiological functions of the body is necessary. For example, a better understanding of the intestinal function and motility in children who experience gastro-intestinal reflux (e.g. Del Giudice, 1997), evaluations of bone mineralisation processes (e.g. Baer *et al*, 1997), (particularly if they are disrupted by drug interactions), and for complex disabilities with epilepsy, drugs may cause appetite suppression causing secondary nutrition problems (Webb, 1980). More information regarding behavioural patterns that can affect feeding management is also needed (e.g. Canadian Paediatric Society, 1994).

The changes in physiological patterns can contribute to changes in growth patterns. It is argued that children with severe neurological disabilities require less energy due to lower activity levels. In some cases, calcium or vitamin D intake may differ from the recommended RDAs because of changes in bone metabolism. Several research groups have developed specific growth reference charts because they argue that comparisons with normal reference data are not valid in such situations. For example, Krick *et al* (1996) developed growths for children with cerebral palsy based on 360 moderately to severely disabled children with quadriplegia, many of whom were tube fed. Growth charts for boys with DMD and children with Down syndrome have also been developed (Willig *et al*, 1993; Cronk *et al*, 1988). However, the charts have yet to be further validated. The charts also raise the question whether we are accepting a lower standard of nutrition and associated risks for children with disabilities? Wide spread use is limited because of the specific population profiles used.

However, it is generally agreed by nutritionists that the growth international data and classifications of nutritional status are valid for all populations (e.g. Kow *et al*, 1991, WHO Working Group, 1986). The WHO Working Group (1986) concluded that individual population specific charts were not a desirable health priority. Some population specific charts have been developed, e.g. Growth reference standards for Indian urban slum children, but require further validation (Seth *et al*, 1990). There is comparable growth of children from higher income groups from developing countries to the international reference data, (mainly collated from higher income countries) (WHO Working Group, 1986). Therefore, it can be

assumed that for children with milder disabilities, or with disabilities that in theory should not cause poor growth, the international reference data is likely to be adequate.

A more fundamental problem is the appropriateness of standard anthropometric measurements (Stallings and Zemel, 1990). Many research groups have noted difficulties in the accurate assessment of height in children with a non-ambulatory status, or in children with kyphosis or scoliosis in the spinal column. Some groups chose not to record height, while others have findings that may underestimate height. The problems can be exacerbated in field studies compared to clinical studies because specialised equipment to facilitate height measurement that are available in clinics may not be practical in field studies. Knee height measured with callipers was found to be a reliable predictor of recumbent length for adults with cerebral palsy and mobility impairments in a clinical setting ($R^2 = 0.78$, $P < 0.0001$) (Hogan, 1999). Body length mats are available for infants, but are not suitable for older children.

The current UN (1986) guidelines are wholly inadequate to offer advice to overcome this difficulty. The guidelines for conducting household nutritional surveys advise not to weigh or measure physically deformed children, as the measurement will interfere with the accuracy of the survey. The guidelines require updating, particularly if a positive message is to be conveyed to carers of children with disability by not excluding the child from such a survey. It is vital the problem is overcome as linear growth can distinguish between short and long term nutritional problems. Suitable methods are required for both research purposes and household nutrition surveys so that cases of malnutrition among children with disabilities are not missed.

Measurements that require only a tape measure are feasible for field studies. Demi-span, (sternal notch to finger roots with arm out-stretched), was found to have a significant correlation with height in a study using healthy European adults ($r = 0.74$ for males, $r = 0.75$ for females) (Bassey, 1986). Detailed arm length measurements (humerus + forearm + hand length) were found to be suitable measurements as an alternative to height in an elderly population ($r = 0.87$ for males, $r = 0.97$ for females, $P < 0.001$) (Mitchell and Lipschitz, 1982). In a large field study assessing the nutritional vulnerability of older people in the developing

world measurements of armspan (distance between the longest tip of one arm to the other), and halfspan (distance between the tip of the middle finger of one arm to the mid-sternal notch), were used (HelpAge International and LSHTM, 1997). Changing skeletal mass and increased physical impairments can complicate nutritional assessments of elderly populations.

Only two field studies have specifically investigated alternative height measurements of children with disabilities [Tables 1.7.1-1.7.4]. Tompsett *et al* (1999) did initially investigate demispan ($R^2=0.87$), but fieldworkers found this a more difficult measurement to take accurately than the halfspan. Mean weight/height, and height/age data were re-assessed with height derived from halfspan prediction equations. No significant differences were identified between the original data and derived data. For example, for children with polio derived impairments, the weight/height data changed from -0.4 to -0.6 Z scores. In the Philippines, Socrates *et al* (2000), used armspan (calculated from halfspan X 2). It was noted that when spasticity was present in both arms the measurement was not useful. The findings of these studies are important for nutritional assessment of children with disabilities everywhere. The usefulness of these measurements requires further confirmations. Lower leg length, as an alternative measurement for height must also be field-tested.

Some research studies focus instead upon techniques that measure body fat/muscle data, such as triceps skinfold thickness or MUAC, which have adequate available reference data (Gibson, 1990). In children with moderate-severe cerebral palsy, skinfold assessments were found to be useful for evaluating the effectiveness of diet or fitness interventions. However, researchers found it was not useful to convert these measures to percentage of body fat because the equations derived from healthy controls were not suitable (van den Berg-Emons *et al*, 1998). A combination of data may prove to be more useful. For example, Tompsett *et al* (1999) felt that MUAC results were greater among the subjects with disabilities because children with orthopaedic or motor difficulties may have increased upper body strength to facilitate movement; thus the data could be misleading with respect to the child's overall nutritional status.

The studies, which investigated feeding difficulties, all concluded a strong association between feeding difficulties and inadequate nutritional status (e.g. Reilly and Skuse, 1994, Socrates *et al*, 2000). However, different methods and definitions of feeding difficulties were used. The studies mainly focus only on oral-motor difficulties. One study found a correlation between poor oral communication and feeding difficulties (Dahl *et al*, 1993). Webb (1980) describes anecdotal examples of children with severe speech difficulties being unable to express opinions about food in the special school/institution. It may be more important in the institution environment than at home where a mother/carer has better understanding of the child's wishes. The concept of oral communication in connection with nutrition is under explored. For example, a child who is unable to verbally or otherwise communicate may not be able to ask for more food. Only one study for children with cerebral palsy from the developing countries investigated feeding difficulties, which assessed feeding independence only by health professionals (Socrates *et al*, 2000). More information is required with respect to nutrition and feeding KAP, as well as other external factors to affect nutritional status. For example, activity is under-explored, but has been noted as a problem anecdotally and specifically in the study conducted by Suzuki *et al* (1991).

Home-based studies are lacking and consequently less is known about children with milder disabilities and feeding problems. The majority of studies investigated children with cerebral palsy (moderate to severe disabilities). Studies with mixed disabilities in the sample have different classification systems, particularly with respect to mental impairments and require careful interpretation. For example, Thommessen *et al* (1991) included children with Down syndrome, rarer cases of girls with Rett syndrome, Fragile X syndrome. Each diagnosis is associated with different growth patterns. In contrast, Suzuki *et al* (1991) gave no clear description of inclusion criteria for the subjects in the group classified as mentally retarded. Descriptive methodology is necessary in all such studies. More larger sample size studies with a heterogeneous population of children with disabilities are required, (although problems of sampling in disability studies were discussed in section I).

A final note regarding future work is discussed. Limited evaluations of interventions have been briefly discussed. However, future work should also include investigating relationships

of nutritional status and child development, for example, cognitive development or stress, which are investigated in children without disability.

It can be concluded that children with disabilities are vulnerable to poor nutrition with further impairing consequences. Much information can be exchanged between globally conducted studies to further address the growing awareness of this problem.

III. The Complexities of Addressing the Needs of the Disabled Child Living in Poverty

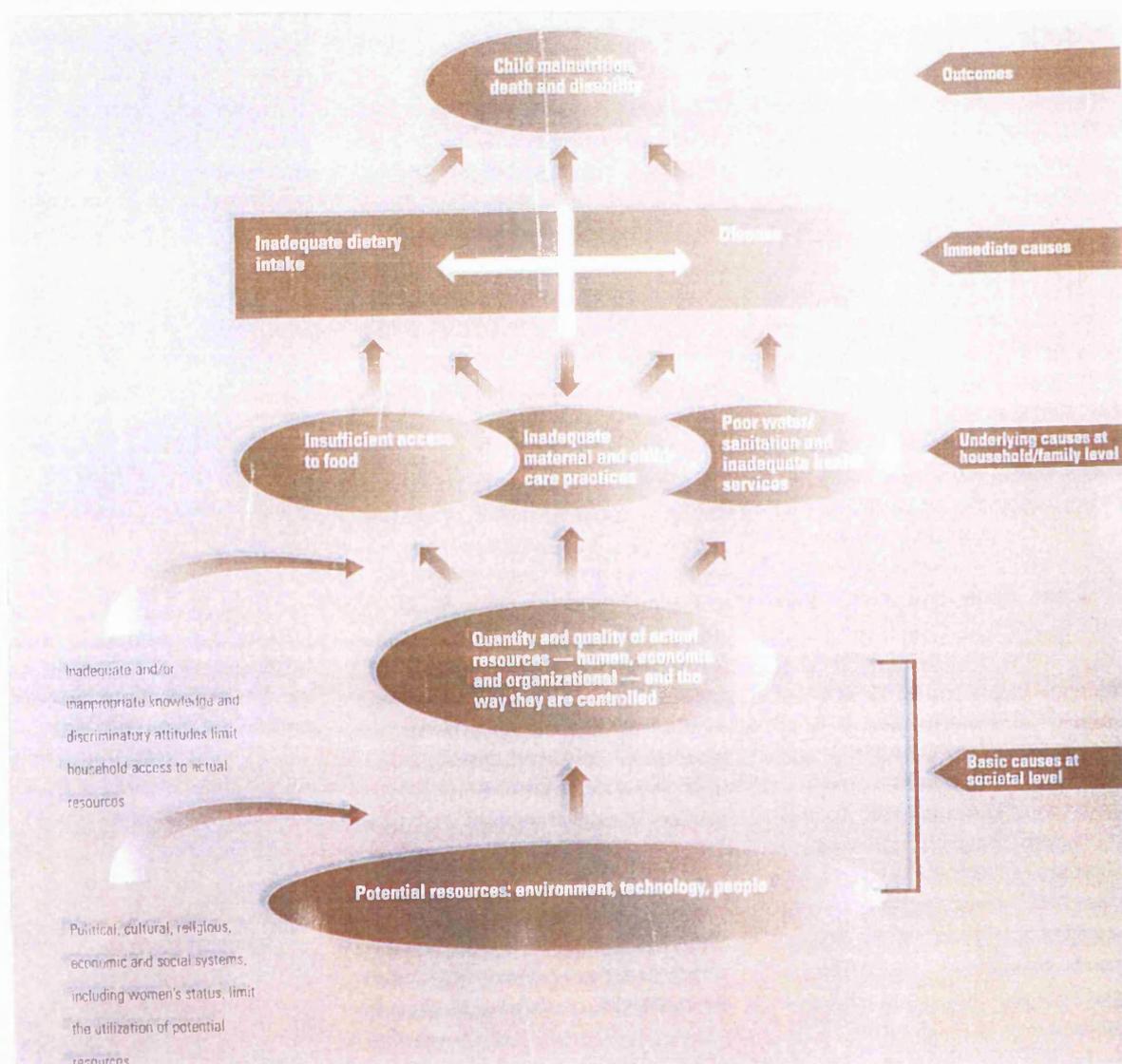
Poverty is both a cause and a consequence of disability. Figure 1.1 described a vicious cycle relationship between poverty and disability. Many of the common causes of disability identified in table 1.2 are prevalent in poor communities, e.g. communicable diseases such as poliomyelitis, and malnutrition.

Two-thirds of people with disabilities are likely to be living in the developing world (Helander, 1992), but only 2% are estimated to have access to rehabilitation and appropriate primary health care and nutrition services (Despouy, 1993). Without access to such services, opportunities for education and social participation is limited. UNESCO have estimated that only 1-2% of children with disabilities in the developing world receive an education (DFID, 2000). Without education, opportunities in the employment market are further reduced. In an environment where poverty itself is considered disabling, it must be demonstrated to the community that addressing the nutritional needs of the disabled child is beneficial for the family. Many people with disabilities are dependent upon carers for physiological, emotional or economic support. Studies have attempted to put a figure on the costs of disabilities (including the loss of earnings to carers) (DFID, 2000). However, there is no simple equation, but the combination of these factors increases vulnerability to further poverty and ill health.

CBR programmes have sought to re-address imbalances for the individual with disabilities. Many of the underlying causal factors of disability are also the underlying external (environmental) factors that contribute to malnutrition. For example, poor water/sanitation, insufficient access to food, and inadequate maternal and childcare practices [Figure 1.8]. The

reduction of child mortality and morbidity through nutrition interventions is still a major goal of global health policies, particularly when malnutrition is implicated in just over half of all child mortality in the developing world [Figure 1.2].

Figure 1.8. Causes of child malnutrition (*The State of the World's Children, UNICEF, 1998*)



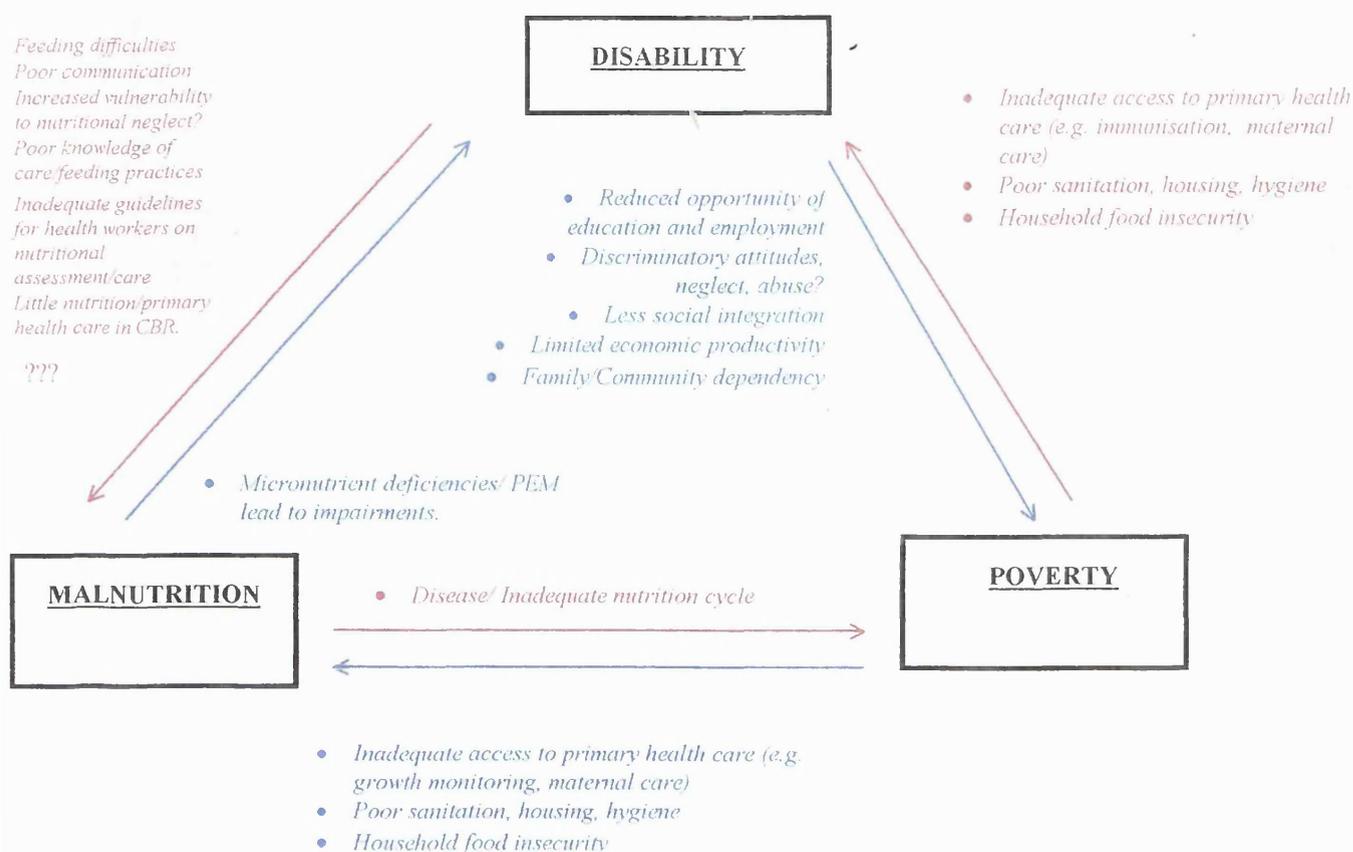
Factors such as inadequate health services are important determinants in health and the early identification of malnutrition. A study in India compared populations living in urban slums; both groups had access to an urban health centre (UHC), but only one group had access to environmental services (e.g. sanitation, housing development). Morbidity among the population with UHC and sanitation services was less. These factors had a significant impact upon disease incidence (Mukhopadhyah *et al*, 1993). Urban populations continue to be low in

developing countries compared with the rural population, but urbanisation is expanding as people seek out better opportunities. Many migrants end up in slum dwellings, which have not been developed to cater for the health care needs of the population (Bose, 1992). The nutritional status of children living in an urban slum in Malaysia found 40% of children aged 0-4 years suffered from acute malnutrition, although methodology is not clearly described (Yap and Teoh, 1989).

The global inequitable distribution of food is linked to household food insecurity. Poor households spend a large proportion of their earnings on food, e.g. approximately 52% of household expenditure is spent on food purchase in Indian homes (ACC/SCN, 1990). At the level of the community and family, young children (in particular the girl child), women and the elderly have been identified as vulnerable to receiving inadequate quantities of food. A study investigating intra-household energy intakes in rural Bangladesh found the intake for women was significantly less ($P < 0.0001$) than the men (Kramer *et al*, 1997). The finding may be explained by the dependency of the household on the economic productivity of the men. Education for people on the value of nutrition for women is recognised as a valuable intervention. Disability and impairment are recognised as consequences of malnutrition, but the vulnerability of children and adults with disabilities is not yet recognised as a potential cause for further malnutrition [Figure 1.9].

By addressing the causes of malnutrition and the issues of inequality, prevention of some disability and disease will occur. However, people with permanent disability will remain in the cycle. The child with disabilities in poverty may face double the disabling consequences. The evidence in the literature indicates that undernutrition among children with disabilities does exist. However, the extent of the problem and all of the underlying causes have yet to be fully explored.

Figure 1.9. A possible relationship between disability, malnutrition and poverty derived from anecdotal and the evidence documented in the literature: "Disability, Poverty and Malnutrition Concept Cycle."



Note: ??? = Concepts of the impact of disability on nutritional status still need to be further investigated.

IV. Disability and Nutrition: Challenges in India

India has the second largest population in the world, (in 2000 it reached 1 billion). It is a country of diverse regions and cultures, and many different levels of economic development. In total there are 24 states and 7 Union Territories. The majority of India's population lives in the rural areas. However, due to a high rate of urban migration, the urban population growth rate (at 1.1%; World Guide, 1997/98) is far higher than the rural population growth rate. Table 1.8 summarises some of the last census data reported (1991).

There is a large burden of poverty among this huge population. A two-track approach towards economic policy, which combines conventional growth and special poverty alleviation

programmes exists (ACC/SCN, 1993). Public expenditure on health and education was 1.3% and 3.5% of total GNP respectively in 1992 (World Guide, 197/98). The provision of adequate services for people with disabilities is a major challenge for the Indian government considering the numbers involved.

Disability in India

There are estimated to be nearly 32.5 million people with disabilities in India and 15 million of this figure are estimated to be children with disabilities (APD, 2000: World Wide Web). Over 70% of disabilities are thought to be preventable. For example, one child in India is affected by polio every 2 minutes, which improvements in immunisation programmes could prevent (Samuha, 2000). Only 2% of this figure have access to disability services. The access to rehabilitation services is not high even in urban areas, where only 5% of people with disabilities receiving appropriate services (Samuha, 2000, World Wide Web).

The services provided for people with disabilities are predominantly in the NGO sector. Organisations such as the Spastics Society of India (SSI) (SSI, 2000, World Wide Web), Samuha, Association of People with Disabilities (APD) run a range of programmes such as community education, therapy, income generation projects, skills training, schools, and advocacy work for people of all socio-economic backgrounds in both rural and urban areas. However, resources are scarce and cannot meet the needs for all people with disabilities. It was estimated that charitable organisations only have the resources to cater for the needs of 0.6% of child with disabilities (Coleridge, 1993). There is growing awareness of disability in India; however, issues regarding disability services appear to still be low on the government agendas. Poverty alleviation programmes will contribute to prevention, but not improve the lives of people living with disability.

Table 1. 8. Census data of India 1991 (Census of India, 1991: World Wide We: <http://www.censusindia.net/>)

Population	846, 302, 688
Rural: Urban Distribution %	74.27: 25.73
Languages	18 official, 3 main: Hindi, Bengali, Telugu
Religions (%)	Hinduism (82.00), Islam (12.12), Christians (2.34),
Total Workers (%)	
• Total	37.46
• Male:Female	51.55: 22.25
Literacy Rate (%)	
• Total (male:female)	52.21 (64.13: 39.29)
• Rural (male:female)	44.69 (57.87: 30.62)
• Urban (male:female)	73.08 (81.09: 64.05)
*School Enrolment (1993) (Source: World Guide 1997/87)	
• Teacher:student (in primary schools)	1:63
• Primary (male: female %)	91: 91
• Secondary (male:female %)	59: 38
No. of Households	
• Total	151, 003
• Rural: Urban	111, 539: 39, 493
Families (% of households)	
• Nuclear	54.2
• Joint/Extended	45.1
Housing Type (%)	
• Permanent	41.6
• Semi-permanent	31.0
• Temporary	27.4
% of household with:	
• Electricity	42.4
• Safe water	62.3
• Toilet	23.7
Houseless Population (% of total population)	
• Rural	0.21
• Urban	0.34
Institutionalised population (% of total population)	
• Rural: Urban	0.30: 1.21

Nutrition in India

Nutrition related problems are highly prevalent in India. 90 million of the 167 million under weight under five-year-olds are estimated to be living in South Asia, mainly in India. The prevalence percentage dropped from 55% to 51% between 1985-95, but because of the population growth the actual numbers increased from 88 to 90 million (UNICEF, 1997). The prevalences of moderate to severe underweight, wasted and stunted children in India between 1990-97 (below -2 standard deviation points from median of population), were 53%, 18% and 52% respectively (UNICEF, 1998). Surveys between 1977-84 indicated the prevalence of mild-moderate anaemia was 66% among pre-school children (ACC/SCN, 1991b).

Indicators of health and nutrition are improving, but slowly. For example, the under fives mortality rate in 1960 was 236 per 1000 live births, and in 1996 it decreased to 111 (UNICEF, 1998). VAD dropped from 2% (1975-79) to 0.7% (1988-90), although this figure is from data collected from only ten states mainly in the South and Central regions (ACC/SCN, 1993). Immunisation coverage and Vitamin A supplementation rates are also improving.

Singh and Yadav (2000), using the WHO 30 cluster survey methodology with some modifications studied 19,000 children. Among this sample, partial or full coverage of polio was 96.8%, BCG was 85.9%, measles was 66.5%, and vitamin A supplementation to be 59.0%. Coverage was variable between states from only 37% of full immunisation in Bihar to 91.9% in Tamil Nadu. Reasons given for non-immunisation included lack of information, and obstacles such as distance from the health facility. Generally, children not immunised were in rural areas and maternal illiteracy was high. The states of Bihar, Uttar Pradesh, Madhya Pradesh, and Rajasthan accounted for one-third of non-immunisation (Bihar and Uttar Pradesh also have high illiteracy prevalence) (Census of India, 1991: World Wide Web).

The contribution of public food distribution has also facilitated improvements in health and nutrition. The programme operates by subsidising rations of rice, wheat, sugar, edible oil, as well as kerosene and standard cloth through 350,000 retail outlets. Universal entitlement is in

place, although the target group is those living in poverty. However, problems exist with coverage, inappropriate targeting and leakage of goods into the free market (Ahluwalia, 1993). The means to achieve household food security (adequate quantity and quality for each family member), still requires an investment of considerable time and energy. A high percentage of household expenditure, which is used as an indicator of household food security, is spent on food (between 50-59%) (UNICEF, 1997). Poverty alleviation programmes are important policy goals for the government.

Integrated Child Development Service (ICDS) in India

Another scheme introduced by the government to contribute to nutrition, health and education improvements is the ICDS. The ICDS was launched in 1975 with the aim of improving health, nutrition, and education of vulnerable pre-school children and their mothers by a holistic approach (ICDS 1975-85, 1989). It is likely to be the largest child welfare programme in Asia. The programme has been criticised for its lack of inclusion of children with disabilities (Alur, 1998). However, in practice children with disabilities are not excluded if they can attend programme facilities (i.e. if access is not inhibited by a lack of mobility) (Dharavi, ICDS Office, 1999). ICDS aims to serve all children. Programmes are organised in rural, tribal, urban, and slum areas. One local woman (an anganwadi worker), and an assistant is employed to have responsibility for 1000 households. The salary is approximately Rs950 for the anganwadi worker and Rs750 for the assistant. Three months training is provided and a network of supervisors is in place (Dharavi, ICDS Office, 1999). In theory, nutritional supplements, growth monitoring, immunisation and pre-school education for the under sixes are provided. Nutritional supplements for pregnant and lactating women are also provided. Practice is variable across different centres (Ghosh, 1997).

A great deal of research has been conducted to investigate the impact of ICDS in relation to nutrition, health, education, and child development in programme areas. Research is predominantly conducted in rural locations (ICDS 1975-85, 1989). Tandon (1989), compared nutritional status of children in ICDS and non-ICDS villages. ICDS selected areas are thought to be similar, thus comparable across the country because they are chosen on set criteria

aiming to reach the poorest of the poor. In this study the non-ICDS villages had been selected to become ICDS areas, but programmes had not yet begun, and were therefore thought to serve as suitable controls. Prevalence of grade III and IV malnutrition in children in 1985 in the control areas was 8.4% compared to 6.4% in areas where ICDS programmes had been implemented for 3-5 years ($P < 0.001$). Over the same period of time normal and grade I malnutrition was 69.5% in the control areas compared to 74.5% in the ICDS areas ($P < 0.001$). The report based comments on data from regular sample surveys conducted on ICDS programmes and did not elaborate any further on methodology. Such data is confirmed other by investigators evaluating collected nutrition data in ICDS area (e.g. Avsm *et al*, 1995).

Chaturdevi *et al* (1989a) present data from two cross-sectional studies of one of the earliest ICDS programmes in Uttar Pradesh (North India). Morbidity data of 400 children in an ICDS area was compared to the data of 357 in a neighbouring non-ICDS area. The mean weight at one year of age of the ICDS area infants was 8.1 \pm 4.4kg compared to 7.2 \pm 1.12kg of control infants. At the time of study significantly less ($P < 0.05$) diseases were recorded for children in the non-ICDS area compared to controls. For example, pneumonia was 3% compared to 5%, diarrhoea and dysentery was 41% compared to 55%, and eye diseases were 7% compared to 7%.

Several other studies have indicated improvements in immunisation coverage, cognitive development, and maternal health (e.g. Tandon and Gandhi, 1992; Pandey, 1991; Chaturdevi *et al*, 1989b; Agarwal *et al*, 2000). The studies vary in sample size, methodology, and it is noted that further in depth studies at national level are required to determine the full impact of ICDS in real terms by independent investigators. However, ICDS has provided invaluable awareness of child health and well-being issues across India.

In a critical review of the ICDS, Ghosh (1997) points out that one of the primary aims of the ICDS was to achieve a reduction in the prevalence of moderate to severe malnutrition among young children by 20% by the mid-90s. The failure to achieve this target and others requires a review of the programme structure and goals. Observers report food supplies are erratic, participation by pregnant and lactating mothers is low (also noted in the study by Agarwal *et*

al, 2000), and the centre is closed for many days and weeks when food supplies run out. Anganwadi workers report that children do not attend when no food is available.

The review criticises the process of growth monitoring of 3-6 year olds. It may be more valuable to monitor 2 year olds for early and effective nutrition intervention (Ghosh, 1989). The process provides data, but occurs without any interaction with the family. The ICDS alone cannot alleviate the many problems faced by those living in poverty, but without interaction through the community and empowerment through knowledge it is even less likely that the needs of the child can be met. Community participation is elusive (Ghosh, 1989).

Tandon (1989) noted comparisons between different ICDS areas across the country were appropriate as all covered households living in poverty. However, regional variations in running programmes and cultural variations may have an impact. The ICDS is organised in a uniform way across India, which may not be entirely suitable (Ghosh, 1997). Training and supervision is also inadequate. Many staff feel the burden of work on an individual anganwadi worker is too much and prevents effective output. There is no doubt, that where ICDS programmes are run under good leadership children and mothers have benefited immensely; however, this is not the case for all the programme areas. The infra-structure of the ICDS is in place as a means for improving child welfare, but without reviewing policies the effectiveness is eliminated, and the potential for including more children with disabilities is reduced.

Slums- The Growing Problems of Rapid Urbanisation

Less information on the impact of ICDS can be found specifically for urban slums, compared to rural, tribal, and other urban areas. The population growth rate in urban areas is high in India. Although urbanisation is often equated with development, there are negative consequences because of pressures on housing and services. India's urban growth is paralleled with an increase in the slum population.

India's most populated city is Mumbai (formally Bombay) in the state of Maharashtra, and it also has the highest slum population (approximately 40% of the population). The 1991 census data calculates a density of 16 400 people per square kilometre in the slums of Mumbai. Half of the slums are on private land, and the other half on land owned by the city council, the state government, and the central government. Historically slums have always been a part of Mumbai. The older slums such as Dharavi and Khar were initially separate villages with specific industries (e.g. tanning). However, the expanding city engulfed these areas. Many policies and programmes to clear slum areas or develop them have been brought forward. For example, in 1983 the Supreme Court ruled that eviction from slums was a disturbance of civil liberty unless necessary for public purposes, and in 1985, a World Bank project was begun for Slum Upgradation (Mumbai Pages, 2000, World Wide Web).

Providing services for this population presents many complications, including a constantly floating population. Older, more developed slums are saturated and are expanding, attracting people from diverse backgrounds with different languages and cultures. Dharavi, the largest slum in South Asia is a prime example. Health and education services cannot cope. Basic necessities, such as sanitation are not in place. For example, too many people must queue to obtain water from a minimal number of public taps. The work participation rate is high among slum dwellers, but mainly in unskilled or semi-skilled jobs; thus, income is often low (Bose, 1992). Illiteracy, child labour, poor housing are some of the common problems found in urban slums.

Consequently, the nutritional status is likely to be poor. Rao (1986) (Bose, 1992) concluded the energy intakes of urban slum dwellers were similar to that of the landless, and lower than the rural average. There is an urban bias in health service provision, but services are not likely to be in the slum areas. An ICMR task force study (1990) (Bose, 1992) found only 25% of urban births are attended by a local health worker, and 41.4% of babies born in urban slums have low birth weight. This and similar studies concluded slum dwellers under-utilise maternal and child health services even when they are theoretically easily accessible. There are 220 ICDS programmes operating in urban slums nation-wide, but community participation is weak (Bose, 1992).

This section was intended to provide an overview of the key challenges faced by programme planners in providing adequate health and disability services in India. Challenges include the large population, remoteness of some rural and tribal areas, the rapid urbanisation process, and diversity of Indian culture. Therefore, research is required before uniformly transferring a successful project (as discussed in section I). Huge numbers of children face poor nutrition and many issues of basic service provision for disability are still to be addressed. However, NGOs are raising awareness and leading the way in providing services at the local and national level.

V. Summary

- There is estimated to be a 4.5% prevalence of disability in developing countries. In 1990, the number of people with disabilities in the developing world was estimated at 4086 million.
- At present there is little collaboration between major public health issues, (e.g. nutrition and primary health care) and the work conducted by DPOs with respect to research and policy.
- There is sufficient knowledge with respect to nutrition to discuss suitable interventions in order to justify screening for disabilities and investigating the nutritional status of disabled children in poor communities.
- Without intervention, malnutrition can lead to death, disease and disablement. An elevated risk of morbidity and mortality can occur in cases of mild to moderate malnutrition. Approximately 7-10 million people were estimated to be disabled as a consequence of malnutrition.
- Vulnerable groups such as women, young children, people in emergencies, and the elderly are noted as important targets for nutrition programmes in the WHO documents.

However, the limited available literature indicates that people with disabilities are also vulnerable to inadequate nutrition.

- The current studies are mainly of a descriptive nature and tend to focus on children diagnosed with cerebral palsy regularly seen in clinical situations. The studies are in agreement in showing poor weight for age data and there are clear associations between oral-motor difficulties and inadequate nutritional status.
- However, we are also aware of other internal (as a direct consequence of the health condition) and external (environmental) factors that can potentially contribute to an inadequate nutritional status that are under explored. For example; knowledge and attitudes of carers, behaviour problems, drug interactions, feeding independence, weakening muscles, and activity status.
- The studies are partly limited by a lack of guidelines to facilitate the measurement of nutritional status.
- Among high-income groups, clinical support to overcome feeding and nutrition problems by a multidisciplinary team is available. In the most severe cases, surgical interventions are an option. However, even in such situations concerns are expressed over the nutrition content of supplementary feeds. Less information is available for those children with milder disabilities and feeding problems.
- In developing countries the situation is complicated by poverty. In countries like India, it is clearly a challenge to alleviate poverty. The nutritional needs of the disabled child may not be noticed. The disabled child living in poverty can potentially be trapped in a cycle of poverty and malnutrition.
- Currently, there is a gap in knowledge of nutrition and disability. More information is required in order to raise the awareness of programme and policy makers of the potential nutritional vulnerability of the child with disabilities.

Chapter II.

Methods

The research focuses on the nutritional health and development of a vulnerable people: disabled children living in poverty.

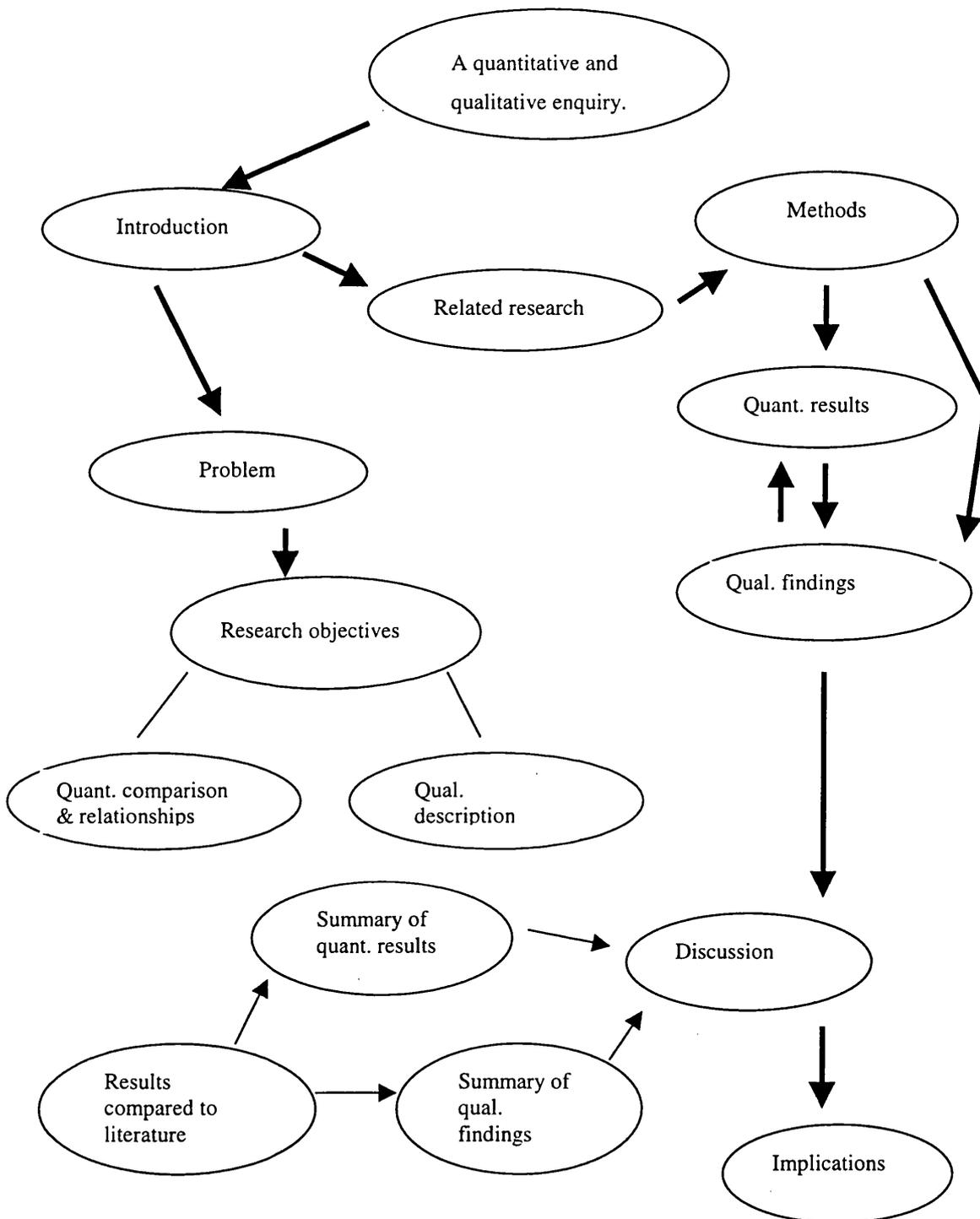
The overall aim of the study was to determine the nature, extent and probable causes of nutritional deficiencies among disabled children living in Dharavi, a Mumbai slum, in order to develop guidelines to promote the health of these children. Any benefits from the study to the children were considered to have potential benefits for the health and productivity of the whole family.

The study was conducted in collaboration with the National Centre for Inclusion, India (NCII), (formally, the National Centre for Cerebral Palsy and other Physical Handicaps, SSI). The NCII in Mumbai was the first centre of the SSI, a national NGO that was set up in 1972. Initially, the SSI ran a special school for children with cerebral palsy, but today it is also active in vocational training and advocacy. The centre has vast experience of disability issues in India, which was useful in the planning of the study. The NGO provided local support and knowledge during the data collection period.

The NCII also have outreach programmes in the slum areas of Mumbai. An integrated pre-school centre in Dharavi served as the opportunistic population sample for a pilot study of nutritional status among disabled children living in Dharavi (Pai *et al*, 2001) (see Table 1.7, Chapter I. Literature Review, pp 70).

The study was designed to provide detailed descriptive data annotated with a variety of factors associated with the nutritional status. Parameters to be explored were determined by a review of current literature. Mixed methodology in order to provide a greater depth to the study was employed in a two-fold research design, thus benefiting from the findings of quantitative and qualitative data collection. Figure 2.1 shows the possible interactions between the different research methods.

Figure 2.1. A concept map of a qualitative and quantitative enquiry (adapted from Gogalin and Swartz, 1992).

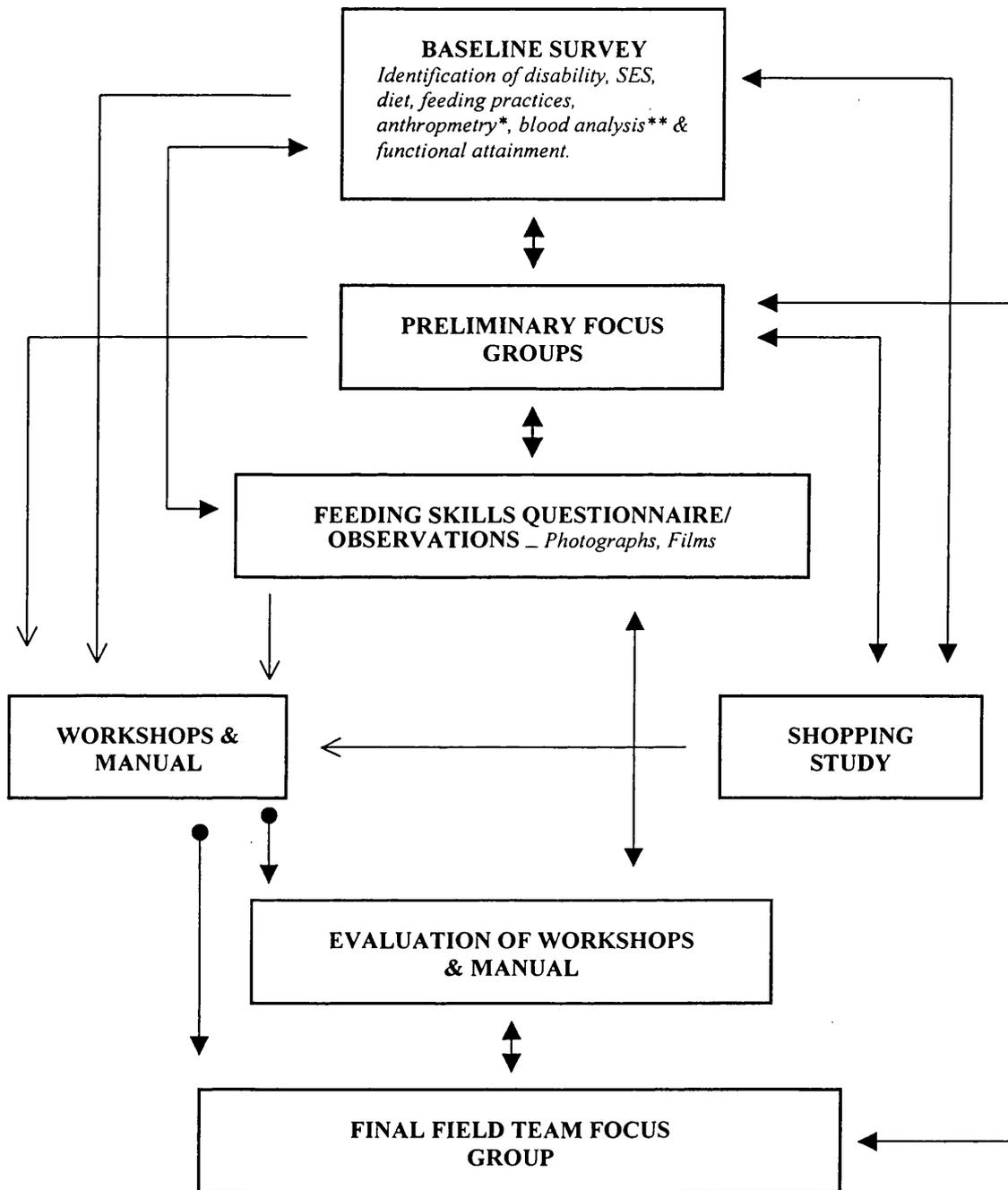


In Stage 1, a case-control baseline study was conducted to determine if the nutritional status of the disabled children was worse than that of the non-disabled children. Possible reasons for any differences identified in the baseline study were explored.

In Stage 2, the improvement of feeding practices was investigated based on the preliminary results of stage 1. One of the common criticisms of qualitative research data is that it is less rigorous than quantitative research data. Therefore, methods for the convergence of the different results and findings demonstrated through the triangulation of data were employed to address this criticism. Primarily triangulation can be used to check the validity of data. The different methods and their interactions with one another used in the present study are shown in figure 2.2.

For clarity, the work is presented in the two stages of the study design. Each stage used distinct research methods for investigating separate objectives. These methods enabled a more in-depth and broad understanding of the impact of disability upon the nutritional status of children living in urban poverty was possible.

Figure 2.2. Research map of data collection.



Note: * = Anthropometry is defined as the measurements of the human body (e.g. height, weight, MUAC, skinfolds, arm length, armspan, tibial length).

**= Micronutrient and Acute Phase Protein (APP) Analysis: Vitamins A & D, ferritin, APP, haemoglobin.

I. Stage 1: The Nutritional Status of Disabled Children, their Siblings and Neighbours Living in Dharavi - A Baseline Survey

The data collection period was between January- June 1999 and November 1999- January 2000. The break in the data collection period coincided with the monsoon season when many families in Dharavi return to their native places for seasonal work.

Hypothesis, Aims and Objectives

The primary aim was to test the research null hypothesis:

“The nutritional status of disabled children living in a Mumbai slum is not different from that of non-disabled children.”

Four key objectives were identified in order to investigate the hypothesis:

1. To understand the knowledge, skills and attitudes (KSA) of carers towards nutrition, feeding practices and disability.
2. To compare the nutritional status of disabled children with their non-disabled siblings and neighbours.
3. To investigate appropriate measurements of height in physically impaired children to facilitate accurate nutritional assessment.
4. To compare functional attainment in the areas of motor, social, self-help, cognitive and language skills.

Study Population

The study was conducted in Dharavi, an urban slum of Mumbai, India [Appendix 1: Maps and photographs of Study Location]. Mumbai is India's wealthiest city with a large port. Consequently, it has always attracted many immigrants from the rural areas, many of whom end up living in either slums or on the streets, (44% of the total population) (Mumbai Pages, 2000, World Wide Web). An understanding of the urban population was a necessary pre-

requisite in order to plan an appropriate research design, particularly because of the many different images and stereotypes people hold of Dharavi. Therefore, Aisha Yousafzai (AY) (Thesis Researcher) made pre-study visits to Dharavi.

The area of Dharavi was originally marshland upon which a village with a small tanning industry developed. Today, the leather goods stores still attract many of Mumbai's wealthier inhabitants and tourists. The early immigrants, who were predominantly fisherman and potters, arrived about 50 years ago. Today, these families occupy the older parts of the slum. With the huge influx of immigrants to Mumbai, the contained area of Dharavi grew into a large and heavily populated slum (Mumbai Pages, 2000, World Wide Web).

Dharavi is located 10km North from the centre of Mumbai and covers an area of approximately 4.5km². It is reputed to be the largest slum in South Asia. The area is divided into Nagars (or Quarters). There are approximately 40 Nagars within the slum. Unfortunately, an accurate map depicting all the Nagars and their respective locations is not available. This is partly because the slum is continuously growing and under constant re-development.

A stable population (many of whom retain close ties with their native places) inhabit the older established areas. These areas are relatively better serviced with a police station, fire station, a primary health care centre, public facilities (e.g. shared taps), and local markets. However, resources are strained. Residents tend to rent their accommodation, and may move rooms frequently. In Mumbai, 50% of the land occupied by slum dwellers is privately owned, while the remaining land is owned by the local Bombay Municipal Council (BMC) and by the State or National government (Mumbai Pages, 2000, World Wide Web).

There is also a constant floating population. Not all of the inhabited areas are legally occupied. Many of the residents do not have ration cards, (which entitles them to reduced costs for basic food necessities through the government's public food distribution system). Such areas are highly under-serviced, particularly by the BMC. The inhabitants are less likely to be counted in a census; they are also more susceptible to illegal practices by local landlords.

The 1981 census stated the population of Dharavi to be 600 000. The growth rate was predicted to be 8.3% per year, which is far higher than the growth rate predicted for the urban areas of India in general, (1.1% per year from 1992-2000) (Bose, 1992; Mumbai Pages, 2000, World Wide Web). There is no single community that describes Dharavi. Immigrants arrive from all over India and tend to settle in groups. For example, one Nagar may have many immigrants from Tamil Nadu and Muslims may mainly occupy another Nagar. Each area has its own sense of community and a variety of languages and cultures are observed. Crean *et al* (1987) conducted an infant feeding survey in Dharavi during which they gathered SES information on 800 households representative of areas covered by the local health posts.. The majority of settlers came from Maharashtra (33%) and Uttar Pradesh (16%). Maharashtra is the state in which Mumbai is the biggest city, while Uttar Pradesh is one of India's poorest states and many people come to Mumbai seeking employment. Cultural sensitivity toward the many differences is necessary, particularly because Dharavi was the worst affected area during the Bombay riots in 1992, which were triggered by religious politics and tensions within some communities are still observable.

Dharavi is an extremely deprived area. 54% of households are estimated to have incomes below the Indian poverty line (Personal Communication at the UHC office, January 1999). The majority of people are employed, but in low-income work. Crean *et al* (1987) found 40% of men surveyed were in casual labour. There are inadequate supplies of electricity and water. Crean *et al* (1987) found 20% of homes surveyed did not have any electricity supply (legal or illegal). People have to queue for water from shared public taps. Supplies are limited and access to illegal supplies is commonplace. However, this leaves some households vulnerable to corrupt suppliers and landlords.

The roads in the area are in urgent need of resurfacing. Open gutters are commonly observed and drainage is wholly inadequate. The pathways are very narrow with little sunlight reaching some areas. This is particularly observed in the newly occupied houses, which are built on marshland, during the monsoon season. The collection of rubbish is infrequent. Many people rely on public bathrooms, which are few. This becomes particularly difficult for the women who must travel a distance to use the toilets. Crean *et al* (1987) report that no houses had toilets, but pre-study observations contradict this fact. Housing committees are now emerging

that have been set up by the residents to ensure improvements in services (Personal communication with a key local informant, January 1999).

Most people rent single rooms (approximately 9ft by 9ft) and live in extremely cramped conditions. New constructions, mainly high-rise flats are being built. The residents in Dharavi can reserve one or two rooms in the new buildings with a deposit. Some people will be displaced in the construction process because the new buildings are replacing the old huts. A relative range of SES groups is observed in Dharavi. However, the vast majority of families will live in households with few possessions and houses with no water supply, toilet or windows. The population is susceptible to an increased risk of infectious and other illnesses.

It is difficult to provide an adequate health service for such a large population. The BMC has set an Urban Health Centre (UHC) on one of main roads of Dharavi, (this is soon to become a Mother and Child Hospital). It is the only government health centre for the entire population within Dharavi. The main hospital is in the nearby suburb of Sion.

A team of CHW and CHW volunteers support the work of the UHC. The UHC has divided Dharavi into five health post areas. Each health post has a clinic, office and dispensary covering a population of 65 000, (the under 5 years population is estimated at 8787). Therefore, the total official coverage is 325 000, (they assume a further 75 000 as part of the estimated floating population). This figure falls far short of the estimated population from the 1981 census of 600 000. The health posts do not cover the new expanding areas of Dharavi.

The role of the CHW is to record births, deaths, offer family planning advice and ensure the children in their respective areas are immunised. The UHC states 98% pulse polio coverage in Dharavi. Immunisation camps are sponsored by private organisations (e.g. the Rotary Club) throughout the year. Some CHWs also participate in informal adult education classes (Personal communication with a CHW at the UHC, January 1999).

In Dharavi, there are approximately 130 private health clinics. These are mainly homeopathic qualified doctors. Anecdotal evidence suggests that the local population is less trusting of the

UHC facilities and prefers private treatment (Personal communication with local doctor, February 1999).

In addition to the pressurised government services there are many NGOs working in the area providing support services. SSI is an example of a NGO, which has a focus on disability and inclusion. Other examples include the Social, Human, Environmental Development group (SHED) and the Shalom Centre, (which has a focus on the education of hearing impaired children). The work covered by NGOs is wide ranging, (including alcohol and drug addiction, leprosy, vocational training and employment opportunities for adults with disabilities).

Dharavi also has 166 ICDS centres. The services are strained and cannot cover all households, leading to inadequate growth monitoring and provision of nutrients. (Personal communication with a supervisor at the ICDS office in Dharavi, February 1999). The classes are held in homes or rented halls, which are crowded. During visits to the Anganwadi centres, children with mild and moderate disabilities were present. There are limited services for disabled children and nutrition programmes are not exclusionary, but are not always accessible to all the families. This may be for practical reasons, for example where a child with severe physical impairments leading to a disability cannot reach the programme. There may be a lack of time on the part of the family because daily survival under circumstances of poverty is both energy and time consuming. However, there may also be a lack of awareness of available services among a population with low literacy. In Dharavi, there are only 4 municipal schools and literacy among the adults is low. Crean *et al* (1987) found that only 47% of mothers surveyed had some degree of literacy. The dropout rate from education was found to be high (Crean *et al*, 1987). The lack of knowledge combined with scarce services or services reaching breaking point result in children with special needs being unable to reach their maximum development potential.

Design of Study

A case-control study was developed. Two control groups (siblings and neighbours) were deemed necessary in order to investigate whether there were any differences between the

nutritional status of siblings and the disabled child, and whether the presence of disability in the family affected the nutritional status of the other children in the family. Convenience sampling was used, which later evolved through a snowballing effect. This was determined to be appropriate given the location layout and the requirement for motivated participants in the study. Local field workers who were trusted by the families initially recruited the subjects. A cross-sectional group of children were recruited for the initial case-control baseline survey.

The sibling control recruited was the child nearest in age of either sex, with no disabilities. The nearest non-disabled, neighbourhood child of the same Nagar, sex and age within 6 months served as the second control. The age range of all subjects was 2-6 years. The age was limited for several reasons: 1) the disability identification tool was limited to children between 2-9 years of age; 2) the functional attainment checklist was only appropriate for children under 6 years of age; 3) it would not be feasible to include older cases in this project who may present with other confounding factors; and 4) it would be practical to develop appropriate early interventions with this age group through clinics and pre-school centres in the future.

In the remaining thesis, the term **case** will be used frequently. However, this will be used entirely to refer to the study design and not as a medical description for children with disabilities.

Population Sample Size of Study

The sample size calculations for the quantitative cross-sectional study were based on recent anthropometric and vitamin A data from India (Ramakrishnan *et al*, 1995; Bhandari *et al*, 1997) and on an estimated anaemia prevalence of 40% in slum children under five years. To show a difference at 5% significance and 80% power, of 0.3SD units in weight/age Z score (the expected most reliable anthropometric measure) 150 children per group were required. This number was calculated to be sufficient to detect differences of 20% in the prevalence of anaemia and in serum vitamin A concentrations between the disabled cases and the two control groups (Kirkwood, 1988). There was inadequate local data about vitamin D status to determine a sample size required for this outcome.

For the preliminary focus groups, representative samples of carers of children in the programme were used. Opportunistic groups of 4-10 participants were invited to attend discussions (Dawson *et al*, 1993). It was decided to use purposive sampling. Participants in the focus groups were selected on the basis of their experiences, which enabled an exploration of the study objectives. By ensuring homogeneity within each group, it was possible to maximise upon any shared experiences (Kitzinger, 1995). Five focus groups were initially planned in the study.

- 1 focus group was held for field workers, (working with disabled children in the area).
- 2 focus groups were held for carers of disabled children, (one group from a relatively better serviced area and the second group from an area with extremely scarce resources).
- 2 focus groups were held for carers of non-disabled children, (one group from a relatively better serviced area and the second group from an area with extremely scarce resources).

This number was felt to be sufficient to obtain reliable findings of the normal attitudes and knowledge. The study was designed to be flexible in case further groups were deemed necessary.

Collection of Data

1. The Identification of Disability [Appendix 2]

Possible identification procedures included the use of home-based growth monitoring cards, (however, it was unlikely that all of the carers would have had these records) with a developmental screening test or a guide for identifying impairment/ disability (Werner, 1987). The “Ten Questions Screen” was finally selected and used to identify children with disabilities and to ensure the control children had no undetected disabilities (Zamen *et al*, 1990). The screen was developed in South Asia for the identification of five major areas of disability, (movement disorders, seizures, cognitive impairments, visual impairments and hearing impairments) in children between 2-9 years of age. It is an epidemiological tool specifically developed for use in developing countries by CHWs. A study conducted in Pakistan found school-attending children could also be trained to use the screen for

identifying children with disabilities within their communities (Saeed *et al*, 1999), which is useful in areas with otherwise scarce health care resources.

The validity of the screen was tested in population-based studies covering 22 125 children in Bangladesh, Pakistan and Jamaica (Durkin *et al*, 1994; Durkin *et al*, 1995). The screen was concluded to be a useful, low-cost and rapid means of identifying moderate to severe disabilities in diverse cultural settings, particularly in areas with little or no disability services. However, there are limitations in detecting mild disabilities, (particularly mild disabilities resulting from hearing and visual impairments). It cannot be considered a detailed assessment tool, but is useful in screening populations at high risk for serious disability (Durkin *et al*, 1995). The usefulness as a preliminary screen of identifying children at risk from further disabilities was confirmed in a study of the prevalence of mental retardation in Pakistan, where the second stage looked at more detailed confirming evidence and evaluations of disability (Durkin *et al*, 1998).

In the present study, the screen was administered in the local language. The understanding of specific terms in the local language was discussed with staff at the NCII before data collection began.

A prevalence rate of 2% of children with moderate to severe disabilities (Helander, 1992) would reveal approximately 3000 case children (using the 600 000 population statistic of the 1981 census), who could potentially be identified for inclusion in the study.

2. Focus Groups: Knowledge, Skills and Attitudes (KSA) [Appendix 3]

The goal of qualitative research is to facilitate the development of concepts, which enables the researcher to understand a subject in the natural, as opposed to experimental situation. Examples of qualitative data collection methods include focus groups, in-depth interviews, case studies, and naturalistic observations. Qualitative methods capture the unpredictability; they permit the exploration of experiences and behaviours that cannot be encapsulated within a quantitative framework alone. Health research frequently utilises qualitative methods to strengthen a study design if the process of data collection and analysis is rigorous with

respect to reliability and validity (Pope and Mays, 1995). The process of qualitative work is continually reviewed for the findings, a descriptive presentation, to be meaningful (Mays and Pope, 1995a, b).

The focus group method specifically utilises the strength of group interaction to enable the generation of these data (Kitzinger, 1995). It is a popular choice for participatory research (Dawson *et al*, 1993). The method was selected in order to obtain a picture of the experiences and understanding of disability within this study site. The qualitative data collection and analysis formed the less-dominant component of stage 1 of the study. The findings of these data served three purposes: 1) to understand the carer's role in feeding and nutrition, which is an important factor in understanding the nutritional status of the child; 2) to inform the quantitative study design and the intervention planning; and 3) to develop a broader understanding of disability and nutrition within this sub-culture because local knowledge and attitudes could not be obtained from structured responses given by carers in the larger survey.

From the documented research and the experiences of key informants of the collaborating organisation, a large level of illiteracy was expected among carers in the study site (Crean *et al*, 1987). The advantage of the focus group is that it does not discriminate against those unable to read or write thus, permitting all opinions to be heard. In the study environment, women are often more comfortable talking in a group with the researcher than in an individual interview. The women are encouraged to discuss issues, like disability, which are otherwise less likely to be discussed.

Nutrition and disability were the central themes for the focus groups. The aim was to obtain descriptive findings of experiences, attitudes and beliefs regarding disability within the area. An enquiry of current knowledge regarding nutrition and feeding practices was necessary. It was felt important for the researcher to obtain a clear sense of the background of the study participants with respect to interests, daily priorities and skills in order to plan appropriate interventions.

The methods of data collection and analysis were determined at the start of the study to ensure a rigorous process of data collection and analysis taking into account reliability and

validity. The planning was also important to ensure that the most marginalised would be included in the data collection process. In order to limit the impact of the researcher upon the discussions, (referred to as the Hawthorne effect), time was planned to allow the AY to become familiar with the study environment and participants. AY is a fluent speaker of Urdu and Hindi.

A focus group facilitator (Mrs. Sunita Pagedar) was selected from the collaborating organisation because of her familiarity with several local dialects. It was also felt that bias in leading the discussion would be limited by excluding any pre-conceived ideas of AY. The observer was AY. Also present was one fieldworker, a local woman whom the participants trusted and respected. Her role was to put everybody at ease. The focus groups were planned to last approximately 35 minutes. The focus groups were held within walking distance and at a suitable time for the participants. Refreshments were offered during the discussion, (these were bought locally). All the people involved sat together on mats laid out to avoid any obvious perceptions of hierarchy. All participants were given a gift of dahl, (again bought locally), at the end of the meeting to thank them for their time. This was clarified on the project information letter verbally conveyed to all study participants.

Observation notes were made in the field diary immediately after the focus group was held in order to avoid distracting the participants. Notes made included all group dynamics, e.g. any hierarchical patterns observed, or if a particular participant was talkative perhaps silencing individuals who were quieter or those with opposing opinions. Each session was audio-recorded using a portable cassette recorder. Transcripts and translations were made within a week of each focus group by AY. A sample of recordings were also translated and transcribed by an independent researcher [Appendix 3: Sample](Mrs. Priyanka Thapyal, MSc student at CICH) to check the accuracy of the work upon returning to England. After each meeting the facilitator and observer discussed any key points that arose from the group meeting, which may have affected the running of further meetings. For example, focus group 2 was held at an unsuitable time of the day and the participants advised us of a better time for our future meetings. A profile of each focus group is shown in table 2.1.

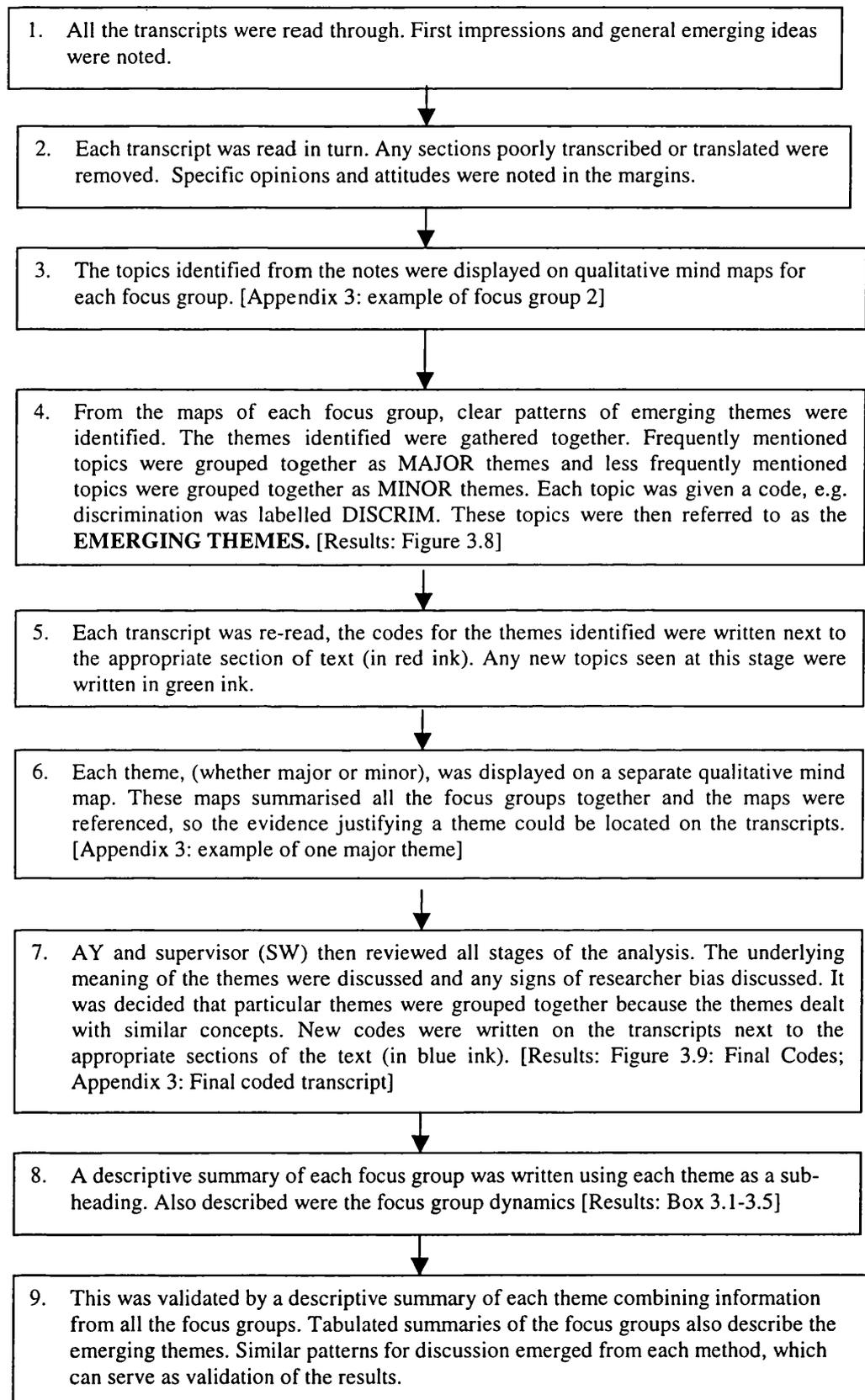
Table 2.1. Profile of each focus group

Focus Group	Date	Time	Participants	Location	Language	Duration
1	26-02-99	11 am	10 female fieldworkers	SSI, Bandra Centre	Marathi (some Hindi)	90 minutes
2	03-03-99	11 am	8 carers of disabled children	Church, Ambedkar Nagar	Hindi	35 minutes
3	10-03-99	2.30pm	5 carers of disabled children	Home of fieldworker, Ragiv Gandhi Nagar	Hindi	40 minutes
4	17-03-99	2.30pm	5-6 carers of non-disabled children	Church, Ambedkar Nagar	Hindi	20 minutes
5	24-03-99	2.30pm	10-15 carers of non-disabled children	Home of fieldworker, Ragiv Gandhi Nagar	Hindi	40 minutes

- Note:*
1. SP translated and transcribed focus group 1 because AY was not as fluent in the Marathi language.
 2. Focus group 1 was not held in the planned location at the request of the collaborating organisation. It was held in the main NCCI centre in the nearby suburb of Bandra.
 3. Two women returned from focus group 3 to attend focus group 5, in order to obtain the dahl.
 4. Only one male participant in focus group 2.

The Municipal UHC, in an older established part of the slum covers Ambedkar Nagar. It is relatively better serviced than Ragiv Gandhi Nagar, which is on illegally occupied land and has no basic amenities or services [Appendix 1]. The data analysis was planned in several stages. These are shown in figure 2.3.

Figure 2.3. Flow chart of focus group data analysis procedure



The qualitative findings were then triangulated with other results [Figure 2.2].

3. The Socio-Economic Status (SES) of the Participating Families [Appendix 2]

A structured questionnaire was developed for investigating information regarding family background, care of children, literacy of carers, employment status and housing status. This was to obtain descriptive information on the study population and to determine whether there were any differences between the case children and control children, which may have an effect upon the nutritional status or influence feeding beliefs and practices. The format was finalised after a review of a previous pilot study (Pai *et al*, 2001) and a preliminary analysis of the focus groups. The parental age was often approximate, (particularly for the father). The age for the child could be given within 6 months by most carers. When carers had difficulty, local events and hints to decide whether the child was born after or before siblings and neighbourhood children were made to determine an approximate age, (a note was made in the data entry book of difficulties). This part of the questionnaire was administered verbally in the local language and answered by a carer who knew the child well.

4. The Dietary Intake of Subjects [Appendix 2]

At the time of the data collection, the researchers were unaware of studies on the dietary habits of children living in an Indian slum. There are a variety of food habits in the different Indian regions. Consequently the collection of dietary intake data is complex. A variety of methods were discussed to explore dietary intake. Food diaries would not be possible given the expected low literacy rate in the community. The 24-hour recall may have revealed an atypical day and may have shown too much inter-variability among the subjects. An indication of quantity was limited due to the many different interpretations of size and kitchen utensils used to show quantity, while weighed intakes would necessitate the participants to have time free for training and then daily measurements.

The food frequency method was selected, which could incorporate the regional differences of food habits found in India (Singhal *et al*, 1998). This was particularly important given the population of a slum comprises immigrants from many states. It would reveal sufficient

information to indicate the typical foods eaten regularly and if there was any significant variance between the subjects. A food frequency list could also provide an informative base for stage 2 of the study. The food frequency could be administered in minimal time and was expected to yield a high response rate.

The food items were selected after a review of the pilot study (Pai *et al*, 2001) and discussions with the social workers at the UHC in Dharavi who have previously run cookery workshops for local women. An inexhaustible food list was decided against because the purpose was not to estimate an actual level of nutrient intake. Parts of the list were open-ended; for example specific fruits were not listed. This was justified because of the expected limited accessibility of foods in an extremely poor area. In addition, the open-ended system provides flexibility in a community where a range of food habits is likely to be observed. At the time of the data collection there was no standard food frequency list available for use in an Indian population. However, Singhal *et al* (1998) were conducting research in order to develop a list specifically for use in a North Indian population.

The table was structured and frequency assessed as advised by Gibson (Gibson, 1993). A semi-quantitative system was selected, which did not enable collection of data on portion size. This part of the questionnaire was administered in the local language and answered by a carer who knew the child well.

5. Related Feeding Practices and Behaviours [Appendix 2]

A structured schedule was developed to examine related feeding practices and behaviours of the case child in order to investigate the presence of any feeding difficulties that may influence the nutritional status, for example, level of feeding independence, time taken to eat meals, difficulties in chewing and level of interaction with other children. Weighted scores were assigned to assess the extent of the problems identified. Responses were from a carer who knew the child well. This part of the questionnaire was administered in the local language.

6. Anthropometry for Nutritional Assessment

AY practised taking measurements at the Growth Clinic of Great Ormond Street Hospital, which includes children with physical and mental impairments. The anthropometric measurements were carried out using standard procedures (UN Guidelines, 1986). A carer for the child was present throughout the procedure. Wherever possible a flat, well-lit area was used as the measuring site. However, not all homes had sufficient space and the lanes outside were not all flat and thus, any discrepancies that may affect the measurement were noted.

Weight was measured to the nearest 0.1kg on standard electronic scales. If the child was unable to stand because of their age or mobility limitation, they were weighed together with the carer and then the carer's weight was deducted from the combined weight. The scales were calibrated regularly during the data collection period.

Length was measured to the nearest 0.5cm using a measure mat (Starters, Norwich, UK) for all children under 2 years of age and for older children unable to stand who were less than 92cm in length.

Height was measured to the nearest 0.1cm using a stadiometer (Leicester Portable Measure, UK). Further measurements were taken to predict height using a flexible tape measure to the nearest 0.1cm (TALC, UK). Armspan measurements were taken from the tip of the middle finger of one arm to the tip of the middle finger of the other arm. Armlength measurements were taken from the tip of the humerus bone to the tip of the middle finger of the left arm. If it was not possible to measure the left arm because of a physical impairment, (e.g. left hemiplegia), the right arm was measured and a note made in the data entry book. Tibial leg length was measured from the knee joint to the ankle joint of the left leg. Again if it was not possible to measure the left leg because of a physical impairment (e.g. the leg was affected by poliomyelitis), the right leg was measured and a note made in the data entry book.

MUAC was recorded to the nearest 0.1cm (MUAC Tape, TALC, UK). The left arm was used unless the subject had impairments limiting an accurate measurement. MUAC cut-off point of below 12.5cm is indicative of mild-moderate malnutrition by a simple screening method

(Gibson, 1990). MUAC changes very little in children under 5 years of age and therefore, is useful in areas where age cannot always be accurately obtained. Tompsett *et al* (1999) found the MUAC results to be greater among the children with disabilities compared to children without disabilities. It was hypothesised that this may be partly because of increased muscle tones in the upper arms among children that were unable to walk and crawled to achieve motility. Therefore, in addition to the standard measurements, skinfold thicknesses were also assessed. Triceps skinfold (TSF) and Sub-scapular skinfold (SSF) were measured to the nearest 0.1mm using standard calipers (Holtain Skinfold Calipers, CMS Weighing Equipment, Ltd, London, UK). The researcher is aware of the difficulties in obtaining accurate skinfold measurements from obese or emaciated children (Harris *et al*, 1984).

7. The Analysis of Micronutrients and Acute Phase Proteins

Haemoglobin was measured as an indicator of iron deficiency anaemia (cut-off below 110g/l indicative of deficiency in children, WHO criteria). A portable HemoCue was used (HaemoCue Ltd, Sheffield, UK). Haemoglobin was assessed at the same time as the anthropometric measurements.

In addition 5mls of venous blood was taken in order to measure serum retinol (Vitamin A), serum 25-hydroxyvitamin D (Vitamin D), serum ferritin, (a measure of iron status) and APPs (indicate infection status). The samples were collected in private clinics in Dharavi (The Mumbai Diagnostic Centre Clinic and the Family Diagnostic Centre Clinic). The study population was comfortable with blood collections from the Government hospital. Samples were then centrifuged for serum separation (3000revolutions per minute (rpm), 10minutes). Duplicate 1ml samples were stored in separate freezers (<-40°C). One freezer was in the clinic and the second at an UHC health post in a nearby Nagar with permission of the health post supervisor. Storage conditions were checked by AY on regular visits. One set was transported to the UK in dry ice for laboratory analysis. Chromatographic assay procedures were used in the serum analysis.

Ferritin was measured by a sandwich enzyme-linked immunoabsorbant assay (ELISA) using both rabbit-anti ferritin antibody and peroxidase conjugated antibody to ferritin from Dako

(Cambridge, UK) and ferritin standards ranging from 0.63-20.00 μ g/l (Beesley *et al*, 2000a). The reference range of ferritin for children between 6 months to 15 years is 7-140 μ g/l. Ferritin levels will increase during iron overload, fasting or inflammatory diseases. Ferritin levels below 10 μ g/l are indicative of iron deficiency anaemia (Tietz, 1995).

C-reactive protein (CRP) is an APP measured by a sandwich ELISA using both capture and horse radish peroxidase-conjugated antibodies to CRP from Dako (Cambridge, UK) and a CRP standard from Behring Diagnostics (Milton Keynes, UK) (Filteau *et al*, 1999). The reference range for adults is 0.2-6.1mg/l and levels are usually lower in infants than for adults. There are no known deficiencies for CRP.

α -Antichymotrypsin (ACT) is a highly sensitive positive APP. It was measured using a turbidimetry assay on a Cobas analyser, with standards ranging from 0.05-1.24g/l (Beesley *et al*, 2000b). The adult reference range is 300-600mg/l. Lower levels are commonly observed in new-borns. Levels of ACT increase during inflammation, malnutrition, infections, tissue necrosis, malignancy, trauma and rheumatic disease (Tietz, 1995).

Retinol was measured by a high performance liquid chromatography (HPLC) assay (adapted from Furr *et al*, 1992). Hexane extraction of retinol was carried out. The sample was then injected through a Luna C₁₈ 5 μ column (Phenomenex, UK) with 100% methanol mobile phase at a 1ml/minute-flow rate. This was followed by ultra-violet detection (325nm, ϵ = 52770) at approximately 2.4 minutes retention time. The internal standard used was all *trans*-retinyl acetate and standards used were all *trans*-retinol (Sigma, UK). The reference range of retinol in children aged 1-6 years is 0.7-1.5 μ l and in children aged between 7-12 years it is 0.91-1.71 μ l. Children show an age-related increase in retinol up to puberty (Tietz, 1995). The international vitamin A cut-off point is 0.7 μ M (Tietz, 1995).

The two main forms of vitamin D are D₂ (from dietary intake) and D₃ (from synthesis in the skin by exposure to sunlight). After synthesis in the skin D₃ is metabolised in the liver and the kidneys to other metabolites effective in the intestinal absorption and transport of calcium and phosphorous (Koshy, 1980). In the present study, vitamin D was analysed by

radioimmunoassay (RIA) (^{125}I RIA Kit, DiaSorin, UK). Deficiency in children is less than 30nM (Lawson, 1999). Deficiencies are observed in cases of malabsorption, rickets, inflammatory bowel disease and anticonvulsant osteomalacia (Tietz, 1995). Seasonal variation is expected in the biochemical analysis of vitamin D (Taylor and Norman, 1984). Vitamin D is one of the more toxic vitamins and can cause disability in high doses (Tietz, 1995).

Table 2.2 summaries the assay procedures:

Table 2.2. Summary descriptions of laboratory assay procedures.

Substrate	No. of Assays	Mean	SD	CV (%)
Ferritin ($\mu\text{g/l}$)	15	54.42	6.69	12.3
CRP (mg/l)	15	7.44	0.44	5.9
ACT (g/l)	6	10.13	0.32	3.2
Retinol (μM)	12	2.36	0.18	7.6
25-Hydroxyvitamin D (nM)	• 3 (High)	72.13	2.30	3.2
	• 3 (Low)	42.11	1.02	2.4

8. Assessment of Functional Attainment [Appendix 4]

Nutritional well-being is associated with other areas of child development, (although no cause-effect relationship between psychosocial development and nutritional status has yet been established). The Portage Checklist was developed in 1969 to help carers teach pre-school children with special needs. The checklist identifies the child's existing range of skills in the areas of motor, social, self-help, cognition and language development. The Portage is used as part of a child development or early intervention programme.

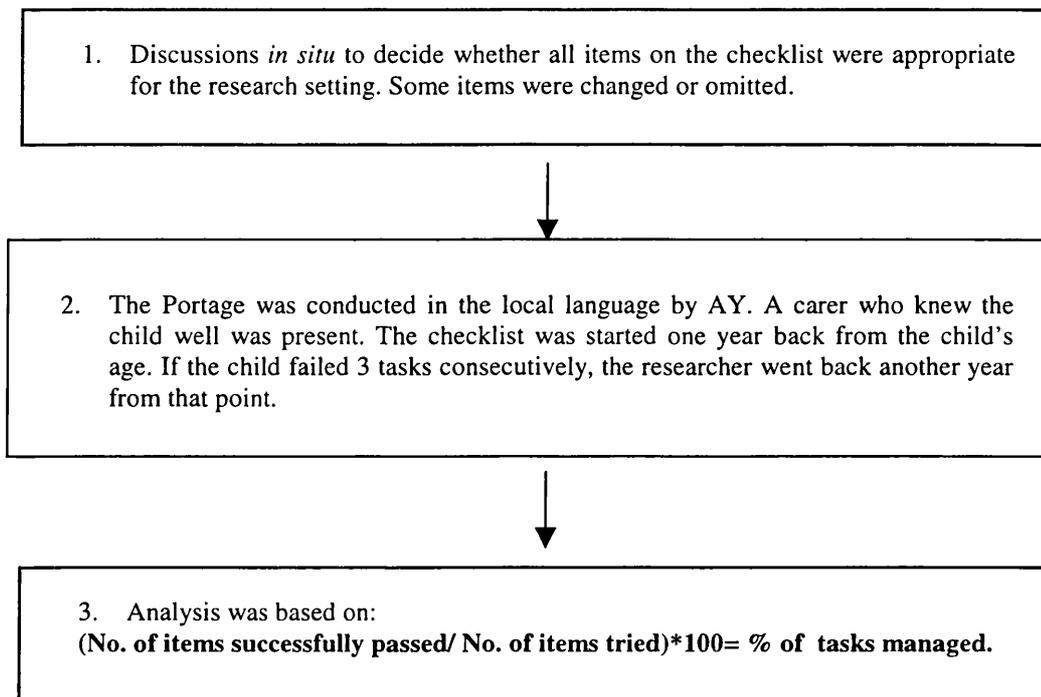
Portage was selected because of the emphasis placed on the child's ability rather than disability. Therefore, as an indicator of functional attainment the method did not discriminate against the case children. The researcher was not aware of other child development assessment tools that have been used for children with special needs. However, the Portage

checklist was developed to assess the needs of children with developmental delays, disability or learning difficulties (Cameron, 1997). A study conducted in Finland found the Portage assessment scale could be reasonably used in a mentally disabled population. One advantage identified was the close relationship to rehabilitation (Arvio, 1992).

Other lists of functional attainment have been developed in India, (e.g. Kumar *et al*, 1995; Vazir *et al*, 1994; 1998). These cover many of the same skills as the Portage. The Portage has been used in many countries of the developing world. However, there are no detailed published papers on Portage in India. Sturmeay *et al* (1992) reported several accounts of Portage services based in India, although not one has been implemented without modification. Some of the programmes recognised the additional problems faced by many families in poor communities such as malnutrition, and often offered a food supplement. There is no universal checklist form used in India. One example is the Krishnaswamy version (1987) adapted for use in the Madhuram Narayanan Centre for Exceptional Children in Chennai, India. It was designed for use in an early intervention programme and thus, limits the age of children to less than 2 years.

A protocol for assessment was designed before data collection began. A protocol for analysis was developed for use in the presence study after discussions with Dr. R. Lansdown (Honorary Senior Lecturer in CICH and Adviser in Education to the Partnership for Child Development, University of Oxford) [Figure 2.4].

Figure 2.4. Portage checklist protocol used in the present study.



An agreed protocol was important because the Portage checklist is not normally used in research to compare children with wide-ranging disabilities to those with no disabilities. It was decided the Portage checklist would be conducted on a 10% sub-sample of the study population in order to determine its usefulness for such a study. The subjects were randomly selected from an opportunistic sample of children participating in the main survey of nutritional status.

The Data Collection Team

10 local female fieldworkers were employed on a casual basis to help identify participants for the study and organise groups for blood collections and Portage assessments. The women had been identified by a mid-level community social worker at the NCII for another project, which was to set up pre-school centres based on the ICDS model, (with a disability inclusion component). The women were to be trained as either teachers or classroom assistants. At the time of data collection, their training with the NCII had not yet begun and their main role was to survey households in selected sites. They also held other jobs, including CHW and ICDS employees.

For the present study, the women were employed to identify participants from across Dharavi. They each came from different Nagars and were trusted by the community. The team was briefed about the project and ethical issues. One woman was trained to administer the questionnaire in Marathi because AY was not fluent in this language. Each woman was paid Rs.950 for working on stage 1 of the project.

The focus group facilitator was a researcher employed by NCII, the observer was AY and one available fieldworker was present during the meetings. All of the other interviews and anthropometry measurements were taken by AY. Two local doctors from private homeopathic clinics in Dharavi took blood and were paid a fee for their work. After discussions with the fieldworkers it was decided to use a private clinic rather than the UHC because often the local population trust the abilities of the staff in the private sector more than at the UHC. Serum separation was carried out by AY. Laboratory assays were conducted by AY and a laboratory research assistant at the CICH (Ms. Abby Woodfin).

The Management of Data

A field diary was kept by AY to record the process of data collection. All discussions with key informants and observations in the field were noted. The focus groups were tape-recorded and transcribed/translated within a week of the meeting.

The anthropometric data was recorded in a data entry book by AY in the field. Subsequently all of the quantitative data was double entered in Epi-info (version 6.04c). The data was transferred to Epi-Nut for conversion to nutrition Z scores (version 2.0). Epi-Nut uses reference data from the American NCHS, which are considered suitable for populations from the developing world (Kow *et al*, 1991)

The Analysis of Data

The database was transferred to the Statistical Package for Social Sciences (SPSS, version 8.0) for analysis. Standard statistical techniques, e.g. analysis of variance and regression, were employed and a 5% level of significance was used.

Children with disabilities were compared with the two control groups to determine the specific effects of disability on the nutritional status. The two control groups were also compared with each other to indicate whether the presence of a disabled child has broader effects on the nutritional status of other children in the household. Case-control analysis was further conducted by sub-dividing the cases into impairment groups. For the disabled children, information on feeding difficulties was also associated with nutritional status. Relationships between armspan, armlength and tibial length with height for the control children were established. Height, (and associated nutritional indicators, e.g. height for age) were then re-analysed for the disabled cases.

The qualitative data was thematically analysed and triangulation was used to validate findings from the focus groups [Figure 2.3].

Ethical Considerations [Appendix 5]

The Ethics Committee of Great Ormond Street Hospital granted ethical permission for the study. Local ethical approval was obtained after consultation with the Preventative and Social Medicine (PSM) Department of Sion Hospital, which oversees the work of the UHC in Dharavi.

Informed verbal consent was a condition for the inclusion in the study. A letter detailing the study was verbally conveyed to all families. The letter explained there was no risk to the child, other than slight pain at the site of blood collection. It was also made clear that a family could leave the study at any time should they wish without any consequences. Written consent was not considered possible due to the expected low rate of literacy among participating families. Translations were done *in situ* with the staff at the collaborating centre.

AY visited each family at home to explain the project. Interviews and measurements were conducted mainly in the child's home at a time suitable to the carer, (although some measurements were conducted outside with the permission of the carer because of the cramped conditions in the home). If a number of children were from the same street or attended the same pre-school then permission was taken for the measurements to be

conducted in either a community hall, classroom or a neighbour's home. An anthropometric measurement is not a painful procedure, but if the child was distressed or in discomfort the measurements were not taken.

All participating children received a course of deworming tablets (Mebendazole), iron and folate capsules, vitamin A capsules and vitamin D capsules. A local doctor (Dr. Neeta Jain) provided the supplements. Each family attending a focus group discussion and a Portage checklist session also received a food parcel (dahl and fruit) to thank them for their time.

All laboratory work was conducted with standard safety procedures. Data was kept confidential and access was restricted only to individuals involved in the collection and analysis. Names were kept off the electronic database.

Dissemination of Findings and Results

The preliminary results and findings of stage 1 of the study were used to inform stage 2. Data from the baseline survey was used in a poster presented at the Oxford 2000 Conference: New Challenges in Tropical Medicine and Parasitology. Internally, a poster was presented at the Institute of Child Health (Annual Poster Presentation for Students, 2000). Feedback from colleagues was also given during a departmental seminar presentation (Centre for International Child Health, October 1999).

Limitations of Study

Local population fears and superstitions limited collection of venous blood. The participation in this part of the study was kept voluntary and 38% compliance was obtained. About halfway through the data collection period it was necessary to change clinics for the procedure. Therefore, collection of blood was stopped for a few months while a new clinic was found which the study population trusted.

II. Stage 2: The Improvement of Feeding Practices

The design of stage 2 was based upon the preliminary results and findings of stage 1. The data collection period was January- May 2000.

Hypothesis, Aims and Objectives

The primary aim of stage 2 was to develop a feasible intervention for the improvement of feeding practices in the home given the scarce resources available for many of the children in the community.

Two key objectives were identified in order to develop an appropriate intervention:

1. To collect data of detailed feeding practices by researcher observation in order to correlate with the findings of the focus groups in stage 1, and to compare carer responses of feeding practices and nutrition with researcher observation. Objective 1 provided informative data that could be useful for low cost sustainable interventions in the future.
2. To run an intervention suited to the environment and needs of children with disabilities and that their carers find useful. Therefore, to determine carer satisfaction of the intervention.

Optimum nutrition can minimise the demands a child with severe nutrition and feeding problems places on a family's time, resources and worry. Improved nutritional status should decrease the burden associated with infectious and other illnesses. Techniques to permit more effective feeding of a disabled child should free parental time for other family duties. The sparing of resources for other family members should benefit their health and productivity.

Design of Study

Stage 2 included only the case subjects (children with disabilities). The study objectives did not require control groups. A cross-section of subjects was followed from stage 1. The aim was to reach at least half of the children from the case-control baseline survey.

The intervention stage was likely to require motivated carers with spare time. It was decided all carers followed up would be invited to participate in the study. The risk was the intervention group would include only the keenest of carers and not necessarily those with children at the greatest risk of nutritional inadequacies. However, at present the overall aim of the intervention was to test whether it is workable in the environment and suited to the needs of the study population. A quantitative follow up of improvement of nutritional status was not possible in this study. Therefore, the risk may be considered small. A decision was made not to exclude any family wishing to participate because it could not be ethically justified.

Collection of Data

1. Observations of Feeding and Nutrition Difficulties [Appendix 6]

A semi-structured questionnaire was designed to assess feeding and nutritional difficulties by carer response and researcher observation. The questionnaire was finalised after preliminary analysis of the results and findings from stage 1 to determine the inclusion subjects.

Part A of the questionnaire asked carers to respond to questions about nutrition, typical feeding practices and typical feeding experiences of their child. A photograph was taken of the child in their usual feeding position. Part B of the questionnaire was a feeding assessment schedule (FAS) adapted for ease of use by non-professionals from Kenny *et al* (1989). The adapted FAS was checked by a speech therapist at the NCCI. The researcher is unaware of the present FAS previously used in a field study.

Each interview was conducted in a familiar environment where the child eats regularly. For the majority of children this was the family home, but for a few children it was in a community pre-school.

2. Illustrative Films of Children Eating a Meal or Snack

Additional observational data was provided by a series of 10 short video films of children eating a main meal of the day or a snack. Families were asked to participate by simple

random selection. This provided illustrative examples of feeding behaviours and practices. In addition it provided a validation source to check researcher observations. The films were made at home or in a pre-school if the child regularly ate a meal during school time. By this stage the researcher was a familiar face in the homes and some of the researcher impact was limited.

In addition the films were observed by 5 objective observers in the UK from the Institute of Child Health and Great Ormond Street Hospital in order to validate researcher observations [Appendix 7].

3. Naturalistic Observations of Shopping Practices and Food Availability in Dharavi

A study of shopping practices was made by naturalistic observations over the period of data collection, (including shopping in local markets), interviews with local women and key informant interviews with social workers at the PSM department of the UHC who have previously run cookery workshops for local women. The shopping study served three purposes: 1) to verify anecdotal evidence collected over the period of data collection regarding food availability; 2) to supplement the information gathered from the food frequency with respect to type and quality of food; and 3) to provide useful information for the planned intervention by broadening the understanding of any constraints for the local population in obtaining adequate nutrition.

The Study Intervention

1. Workshops for the Improvement of Nutritional Status and Feeding Practices [Appendix 13]

The selected intervention was a series of workshops for the improvement of nutritional status and overcoming feeding and drinking difficulties faced by children with disabilities. The content of the workshops was finalised after a review of the preliminary data and discussions with CHWs *in situ*. The following components were included:

- The importance of good feeding skills and nutrition
- Nutrition
- Feeding positions
- Feeding and drinking skills
- Encouraging independent feeding
- Information for children with visual impairments
- Oral hygiene
- Cooking demonstration using locally bought affordable foods and commonly used equipment. Examples of other food items were also shown (healthy and cheap, e.g. jaggery [molasses])
- Information with regards to useful local services, (e.g. immunisation, therapy, availability of free course of deworming tablets)

The advantages of the workshops were the opportunities provided to convey knowledge of information to improve the care of the child with disabilities and for carers of children with disabilities to come together and share experiences. The findings from the focus groups of stage 1 and the anecdotal evidence suggested that the carers (often the mother) usually did not meet other carers of a disabled child and felt isolated or unable to talk about the situation. Some of the knowledge would also have broader benefits for the other children in the family, (e.g. information with respect to nutrition, deworming or immunisation). The preliminary findings suggested carers of children with disabilities had very little awareness of available services in the local area that could benefit the disabled child and their siblings.

Four workshops were run lasting approximately 2 hours each in the early afternoon [Table 2.3]. Four sites were selected in four different community locations, (e.g. free ICDS centre, grounds of community hall). The carers were invited about a week before the workshop and then repeat visits were made on the morning of the session. Each session was held in Hindi and Marathi. The women were free to ask questions and flexibility to permit time for discussions was planned. The option of home visits for children with severe feeding difficulties was given. Local CHWs were also invited to the workshops.

The cooking demonstration was designed to demonstrate means by which the nutritional content of an everyday meal could be improved. It involved voluntary participation of attendees and covered a range of discussion items such as hygiene and texture of food. At the end of the workshop, the carers each took a portion home for their children's lunches as the workshop would have taken time away from their household chores.

Table 2.3. A summary of the workshops held in Stage 2.

Workshop	Date	Time & Duration	No. of Participants	Location	Language
1	15-03-00	2.30pm 2hrs	15 carers	Grounds of Urban Health Centre	Hindi (and a little Marathi)
2	16-03-00	2pm 2hrs	13 carers	ICDS Centre No.5	Hindi
3	18-03-00	11am 2hrs	4 carers	Community Hall (Ragiv Gandhi Nagar)	Hindi
4	18-03-00	2.30pm 2hrs	8 carers	Urban Lines, Participant's home.	Hindi

Note: Approximately 12 community health workers also attended and 10-15 additional local women living in Dharavi (interested neighbours).

2. The Workshop Manual [Appendix 8]

A manual called "Feeding Disabled Children- A Guide for Carers in Dharavi" was developed to complement the workshop. A local schoolteacher using locally understood Hindi translated it into written Hindi. The manual was predominantly of a pictorial nature, which was intended to trigger reminders of the topics discussed in the workshops. A detailed written manual would have been less useful in an area with little literacy. Each carer could take home a copy of the manual if they wished.

3. Satisfaction of Workshops and Manuals by Carers [Appendix 9]

A semi-structured questionnaire was developed to obtain feedback with respect to workshops and manual from attendees. The main aim was to see whether the information was clearly conveyed by the team. We also wished to determine whether the carers remembered information and whether they felt it was practical for their circumstances.

4. Final Field Team Focus Group [Appendix 10]

At the end of the study, a final team focus group was conducted. All the fieldworkers involved in the research and the other CHWs that had attended workshops were invited. The aim of the discussion was to gather feedback on the workshops and ideas with regards to programmes on nutrition and disability in the future. The focus group was conducted in Hindi and notes on the discussion were made immediately after the focus group session by AY.

The Data Collection Team

One local fieldworker (Mrs. V. Jadhau) was employed part-time (Rs.950 a month) for the data collection period between November 2000- May 2001. Her role was to facilitate the identification of participants, finding participants from stage 1, helping to organise workshops and facilitate interviews conducted in either Marathi or Tamil. Her main work was a part-time CHW for the UHC in Dharavi, with work experience of nutrition and health projects. The questionnaires were administered by AY. The workshops were conducted by AY with the assistance of Mrs. V. Jadhau.

The Management of Data

A field diary was maintained throughout stage 2 of the data collection period. All discussions with key informants and observations in the field were noted. The quantitative data was double entered in Epi-info (version 6.04c). The focus group notes were made immediately after the sessions. The video films were transferred to a standard VHS cassette upon returning

to the UK from the Medical Illustrations Department of the Great Ormond Street Hospital, London.

The Analysis of Data

The database was transferred to SPSS (version 8.0) for analysis. Standard statistical techniques were employed and a 5% level of significance was used. Correlations between researcher and carer observations were conducted. Objective researchers completing film observation questionnaires validated all observations. Qualitative data was thematically analysed and validated through triangulation with other data [Figure 2.2].

Ethical Considerations

Verbal consent was again asked as a pre-requisite for inclusion in stage 2 of the study. Permission was also asked from the carers for photographs or films to be taken. Each family was given an additional photograph of their child. The carers were also given dahl and fruit as gifts for attendance of the workshops. All data was kept confidential and access was restricted only to individuals involved in the collection and analysis. No names were entered in to the database.

The Dissemination of Findings and Results

Carers kept the manuals developed to accompany the workshops. Additional copies were distributed to the NCCI out reach project staff, and other CHWs who attended the workshops. The study findings will be disseminated through the scientific press.

Limitations of Study

Many subjects were not located on follow-up because of relocation within Dharavi or returning to native places. Also, in December 2000, a fire occurred in one of the larger Nagars (Ragiv Gandhi). 4500 homes (Bombay Times Report, December 2000) were lost and many people were displaced while the re-building happened. Others moved to new locations

within Dharavi. Extensions of the railway system also meant many homes along the railway line were lost and more people were displaced in February-March 2001. During this period it became difficult to find many subjects to invite them to participate in Stage 2.

However, a strong network of contacts had been established within Dharavi to help overcome barriers during the process of data collection, which enabled completion of the study.

Chapter III.

Results

The numbers of subjects recruited for the present study are shown in table 3.1.

The sample size calculations indicated that 150 subjects were required per group to show a difference, at 5% significance and 80% power, of 0.3SD units in weight/age Z score and 20% differences in the prevalence of anaemia and vitamin A concentrations between the disabled cases and the two control groups. 141 cases were identified through the convenience sampling method, however, this made a minimal difference to the power size that was reduced from 80% to 76%. Therefore, the number of cases per group was sufficient for the analysis process.

Table 3.1. Summary of participating subjects.

	Disabled Case Group	Sibling Control Group	Neighbour Control Group
n (male:female)	141 (69:72)	122 (60:62)	162 (83:79)
Mean Age (m) (SD)	54 (20)	55 (27)	52 (17)

Note: 1. Taking the case- matched neighbour controls only (n=141) the male:female ratio is 69:72 and the mean age (SD) is 53m (18).

2. 19 siblings were unavailable to serve as a control (12 cases had no siblings, 3 siblings were either adults or teenagers and 3 siblings were in their native places).

141 neighbours were used as case-matched controls (matched for age within 6 months, sex and Nagar). The remaining neighbour children served as additional data and only anthropometric and haemoglobin information was collected. Generally, these children were brought to anthropometry sessions by local carers who had heard of the study.

The results of the study are presented in the two stages described of the data collection process, described in the Methods chapter, answering the relevant study objectives. The order of presentation is presented below:

Stage 1: The nutritional status of disabled children, their siblings and neighbours living in Dhàravi- A baseline survey.

Objective 1-To understand the knowledge, skills and attitudes of carers towards nutrition, feeding practices and disability.

Objective 2- To compare the nutritional status of the disabled children with their non-disabled siblings and neighbours.

Objective 3- To investigate appropriate measurements of height in physically impaired children to facilitate accurate nutritional assessment.

Objective 4- To compare functional attainment in the areas of motor, social, self-help, cognitive and language skills.

Stage 2: The improvement of feeding practices

Objective 1-To collect data of detailed feeding practices by researcher observation in order to correlate with the findings of the focus groups in stage 1, and to compare carer responses of feeding practices and nutrition with researcher observation.

Objective 2-To run an intervention suited to the environment and needs of children with disabilities and that the carers find useful.

I. Stage 1: The Nutritional Status of Disabled Children, their Siblings and Neighbours Living in Dharavi- A Baseline Survey.

141 disability cases were identified using the “Ten Question Screen”. The questionnaires were then reviewed and the cases classified into 6 groups [Table 3.2].

Table 3.2 Classification of the 141 disability cases.

Group	Classification	n (male:female)	%	Notes
1	Neurological Impairments	55 (28:27)	39	Includes children with cerebral palsy only, cerebral palsy and one other impairment or a combination of 2 or more other classification groups.
2	Motor Impairments	28 (14:14)	20	Includes children with post-polio syndrome, clubfoot, amputee, other mobility difficulties, and accident-acquired disability.
3	Speech Impairments	23 (8:15)	16	Includes children with cleft lip and palate, those who were non-verbal or verbal with speech/ communication difficulties. There was no obvious deafness.
4	Sensory Impairments	17 (6:11)	12	Includes children with blindness or low vision, deafness and partial hearing.
5	Learning Capacity Impairments	14 (9:5)	10	Includes children with Downs Syndrome and ideopathies.
6	Epilepsy	4 (3:1)	3	Includes children with recognised fits not related to fever.

Children in Group 3 classified as having speech impairments may have been emotionally disturbed or were likely to be learning/neurologically impaired without obvious signs presenting. The information was limited in being able to unequivocally classify these children

into the other groups. Therefore, it was decided to create a speech impairment group rather than risk an incorrect classification.

The SES of the 141 disabled children and their matched controls was compared to identify any significant differences between the groups that should be considered with each study objective. No significant differences were identified by T-test between the case and control families with respect to: 1) family background, 2) carer background, and 3) housing and possessions. A descriptive summary of the study population is presented.

1. Family Background

The mean length of time families had lived in Dharavi was 10 years, (ranging from a few months to more than 40 years). 71% of the families were new migrants, (defined as living in the area ≤ 10 y) [Table 3.3]. Crean *et al* (1987) found 59% of families surveyed were newer migrants.

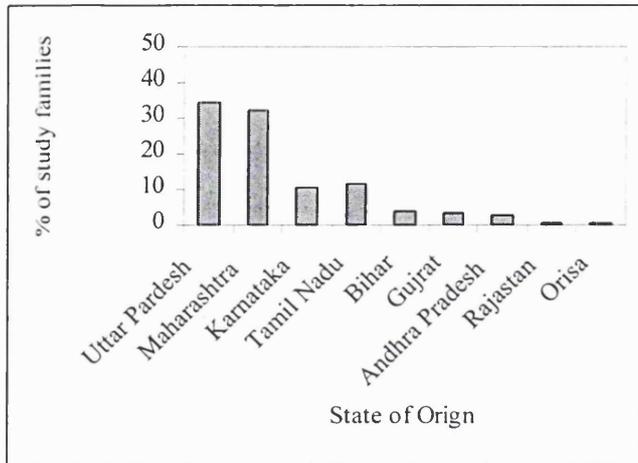
Table 3.3. Length of time study population has lived in Dharavi.

	n= Case Families	n= Control Families
≤ 10 y	89	68
>10 y	30	32

Note: Differences in proportions not significant.

14% more of the case families compared to the control families were described as new migrants. Anecdotal evidence suggests that some families with disabled children migrated to the city specifically seeking health services for their child. The families had migrated to the slum from a range of states and Union Territories across India [Figure 3.1].

Figure 3.1. State of origin for families in the study population.



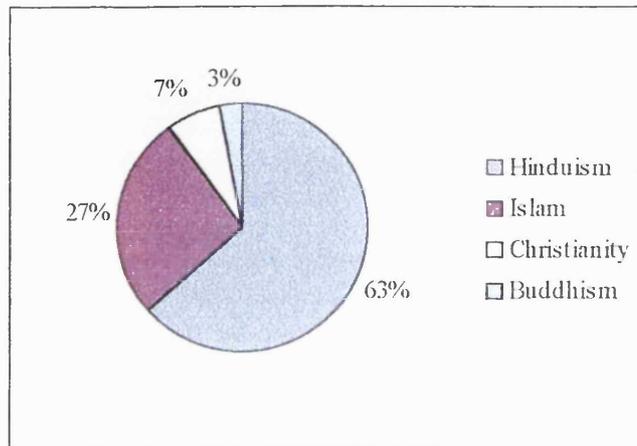
The majority of families originally came from Uttar Pradesh (34.3%) and Maharashtra (32.2%). A similar observation was made by Crean *et al* (1987). Maharashtra is the state for Mumbai and many families from the smaller towns and rural villages migrate to Mumbai, (anecdotal evidence suggests this is in search of work). Uttar Pradesh is recognised as one of the poorer states of India with a high number of landless labourers; thus people leave to seek greater employment opportunities elsewhere. A situation similar to Uttar Pradesh also exists in Bihar. Gujarat, Andhra Pradesh and Karnataka all share a border with Maharashtra, which may explain, some of the migration drift towards Maharashtra, (and in particular Mumbai).

Many of these families have settled in Dharavi after leaving rural areas. However, the ties with their native place remain. Families may send some children back to live in their native place or they may return for seasonal agricultural work.

A similar distribution was revealed across the states of origin between the case and control families. A requirement for matching controls was that the family should live in the same Nagar as the case child. It is common to find Nagars inhabited by people of the same culture or religion, thus explaining the observation. Appendix 1 shows the distribution of subjects across the different Nagars of Dharavi.

Figure 3.2 shows the different religious groups represented within the study population.

Figure 3.2. The different religious groups represented within the study population.



The distribution pattern of religious groups reflects those seen in India (see Table 1.8, Chapter I. Literature Review, pp81). The proportion of Buddhists was higher than the national proportion, but Buddhists are the 3rd largest religious group represented in the state of Maharashtra. The number of Muslims was also higher within the Dharavi study population. However, this may be reflected by the large number of migrants from Uttar Pradesh and Bihar [Figure 3.1] where the Islamic population is higher than the national figure (17.3% and 14.8% respectively) (Census of India, 1991, World Wide Web). Christianity is also a highly represented group along the West Coast of India reflecting the higher proportion in the Dharavi study population compared to the national figure. Crean *et al* (1987) found a similar spread of religious groups in their study (Hinduism- 60%, Islam- 28%, Christianity- 8% and Buddhism- 3%).

Data on family background was deemed important from the review of literature because India represents many cultures with different dietary habits that may have proven to be an important consideration in the analysis of results for nutritional status.

2. Carer Background

In addition to the family background information, there is a strong body of evidence to link maternal education with the health status of the child as suggested in the review of literature. Therefore, data were collected on the background of the carer^{3.1}, (e.g. literacy rates, employment status).

The mean age of the mother and father of the case child (28.4y and 33.8y respectively) was significantly higher ($P < 0.05$) by paired t-test than of the control child (26.9y and 32.0y respectively). However, it should be noted that the interviewee frequently estimated parental age, particularly when a mother was questioned about the age of the father of the child. Table 3.4 shows a general trend that the disabled children's parents were older than the parents of the neighbour control children's parents.

Table 3.4. Age of parents in study population.

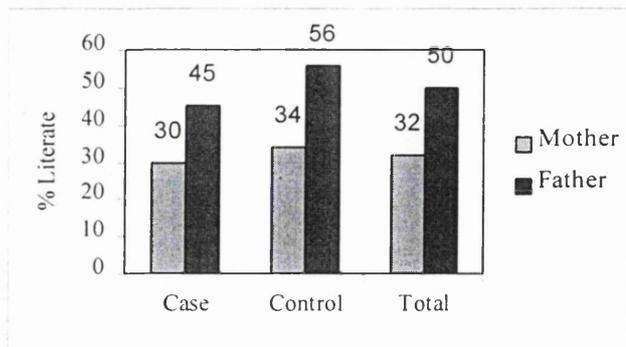
	n= Case mothers	n=Control Mothers	n= Case Fathers	n= Control Fathers
≤ 20y	2	10	1	0
21-25y	38	51	3	16
26-30y	64	41	38	48
> 30y	20	16	78	50

Note: Differences between cases and controls were not significant.

Data on the literacy rates of both parents was collected [Figures 3.3 and 3.4].

^{3.1} The information was usually collected on the mother and father. However, where the parents were deceased or for another reason the child was raised by other carers the information was collected on that primary carer and noted on the questionnaires.

Figure 3.3. The literacy prevalence of parents (or main caregiver) among the study population.



Note: 1. $n=141$ per case-control group.

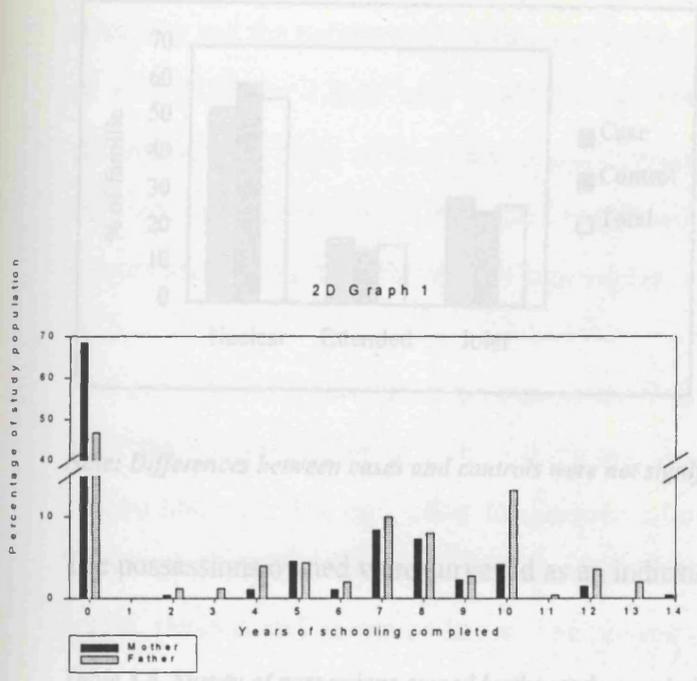
2. 4 mothers and 1 father were only literate in Urdu (mainly used by Muslim population).

3. Differences between cases and controls were not significant.

Literacy was slightly higher, but not significantly, among the parents of the neighbour control children compared to the parents of the disabled case children. Information on the number of completed school years was also collected [Figure 3.4]. Of the carers, that do attend some schooling, most drop out between years 7-10.

The literacy and schooling figures for both sexes is far lower than national figures shown in the 1991 census of India. This is not surprising when one considers that Dharavi generally attracts the poorer migrants. Crean *et al* (1987) found the study population was generally more literate than the national average.

Figure 3.4. The number of school years completed by mother and father (or main caregiver) of the study population.



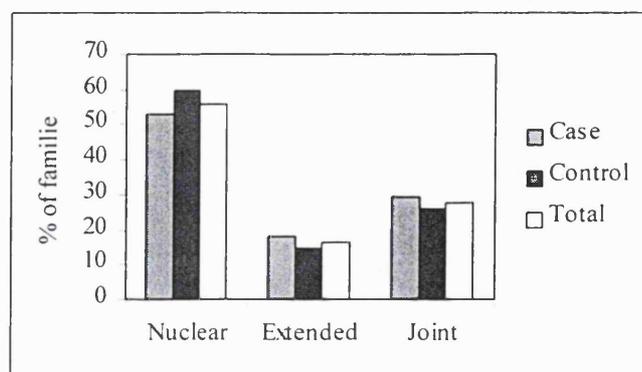
	% Case	% Control	% Total
Bed	43.3	44.9	44.0
Chair	23.5	33.7	29.0
Light	62.4	63.8	63.1

- 1. n=141 mothers, n=141 fathers.
- 2. Year 13 represents a completion of schooling with the final board exams, Year 14 represents a degree at the Bachelor's level.

Information on paternal employment status was collected [Figure 3.5]. Of the total number of unskilled labourers (n=119), 58% were fathers of a child with a disability and 42% were fathers of the neighbour control children. The level of unemployment was low (n=12, 4.7%) in agreement with Crean *et al* (1987).

In summary 282 families (141 case and 141 control) were surveyed for SES information. No significant differences were identified between the cases and controls that could potentially serve as confounding factors in the analysis of the main study objectives.

Figure 3.7. Type of family household for the study population.



Note: Differences between cases and controls were not significant.

The possessions owned were surveyed as an indicator of wealth [Table 3.6].

Table 3.6. Survey of possessions owned by the study population.

	% Case	% Control	% Total
Bed	43.3	44.9	44.0
Chair	25.5	33.1	29.0
Light*	62.4	63.8	63.1
Fan	57.4	56.0	56.7
Television	47.5	53.5	50.4
Stored Food	24.8	24.4	24.6

Note: 1. *= light/electricity. Often this was not a legal supply.

2. Differences between cases and controls were not significant.

The ownership of possessions was similar between the case and control families with no significant differences.

In summary 282 families (141 case and 141 control) were surveyed for SES information. No significant differences were identified between the cases and controls that could potentially serve as confounding factors in the analysis of the main study objectives.

This was a case-control study with subjects identified through convenience sampling. Such a study design was necessary because the study was dealing with the sensitive issue of disability and the numbers of suitable and willing case subjects from an estimated population of >600 000 over 4.5km² area would be low. Also active participation would be required in the intervention stage of the study. A true representative sample from random selection was thus not feasible. However, the cases comprised a large heterogeneous group covering 34 Nagars across Dharavi (Dharavi has approximately 40 Nagars).

However, the data revealed a poor population and low literacy with immigrants migrating from the poorer regions of India, which may have been hypothesised from the review of current literature. The only other documented information that could be found on the Dharavi population was from the study by Crean *et al* (1987), which had similar findings with respect origin, religion and accommodation. The present data shows poorer literacy rates and more new migrants. However, the time difference was large and the population has grown enormously (estimated 8.3% growth rate). Crean and colleagues worked in the 16 Nagars covered by the Bombay Municipal Council (BMC) out-reach services, but since that period the area has grown and the present study had subjects from 34 Nagars, which unfortunately cannot all be reached by the over-stretched education and health services. The subjects are likely to show typical examples of families from these Nagars. It is from this group of subjects that the study objectives were investigated.

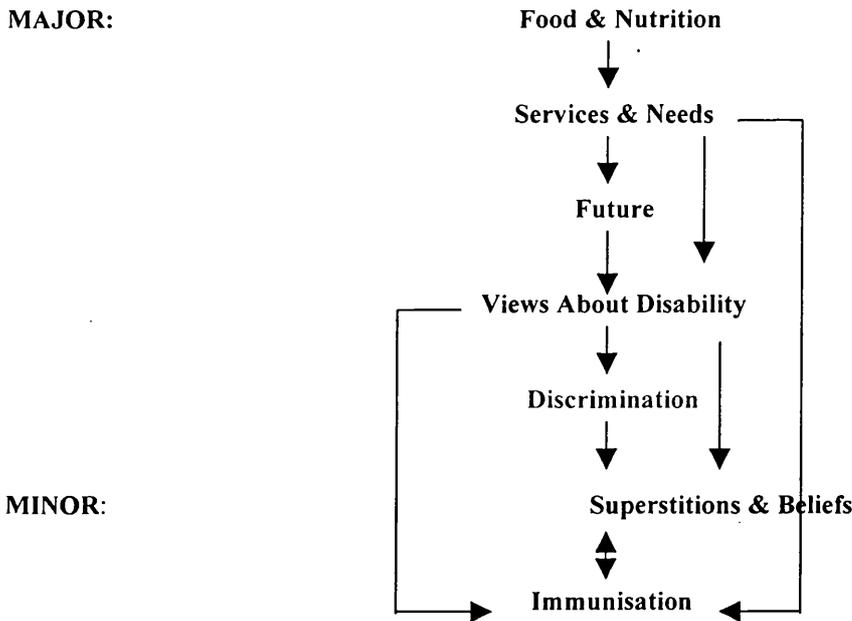
Objective 1: To Understand the Knowledge, Skills and Attitudes (KSA) of Carers Towards Nutrition, Feeding Practices and Disability.

Opportunistic groups of carers from the study subjects participated in focus group discussions (see Table 2.1 for profile of participants, Chapter II. Methods, pp108). The purpose was three-fold; 1) to understand the carer's role in feeding and nutrition (an important factor in determining the child's nutritional status), 2) to inform the quantitative dominant phase of the study, and 3) to develop a broader understanding of disability and nutrition within this sub-

culture because local knowledge and attitudes could not be obtained from structured responses given by carers in the larger survey.

After analysis (see Figure 2.3, Chapter II. Methods, pp109), the MAJOR themes emerging from the discussions were: **food and nutrition, services and needs, future, views about disability, and discrimination.** The MINOR themes were **superstition and immunisation.** An additional theme of **poverty** was raised frequently. However, this was an underlying factor in all areas of discussion. For example, comments relating to **needs** or **food** could not be separated from **poverty**. Figure 3.8 illustrates the relationships between the themes. No theme was completely isolated from another.

Figure 3.8. Links between the themes initially identified from the analysis of the focus groups.

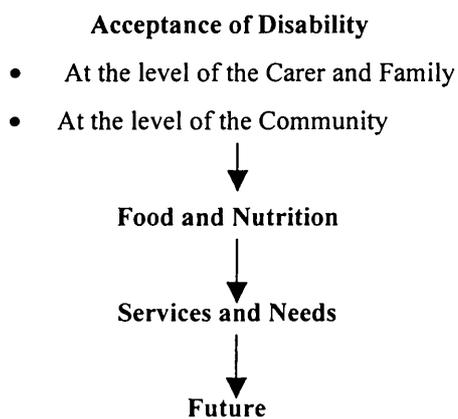


Note: The arrows indicate the inter-relationships between the initial emerging themes.

The inter-relationships permitted themes to be grouped together [Figure 3.9]. The final groups were: **acceptance of disability at the family and community level** (including the MINOR

themes and the MAJOR themes of **discrimination/views about disability**)^{3,3}, **food and nutrition, services and needs, and the future.**

Figure 3.9. Final themes selected for focus group analysis.



A descriptive summary of each focus group discussion is presented using each group of themes as a sub-heading [Boxes 3.1-3.5].

^{3,3}It was felt that the interpretation of **discrimination** was misunderstood in the present context because of the different attitudes in more affluent areas compared to a culture in poverty.

Box 3. 1. Focus group one – fieldworkers (10 participants).

At the time of the focus group the fieldworkers had not yet received any formal training from the collaborating centre, and had only just begun to survey their local community for another NCCI project. However, one participant had previously worked for the ICDS. Two were completing a diploma course in social work at a local college. All of the participants were literate and most were married with families. Marathi was the mother tongue for 9 of the fieldworkers, but all were fluent Hindi speakers. It is worth noting that the focus group discussion was held in a less familiar setting to the participants, leading to some discomfort. Only one participant was very quiet and shy to discuss her opinions.

Acceptance of Disability

a) At the level of the Carer and Family

It was felt that some parents experienced feelings of shame if their child was born with a disability. When the fieldworkers are surveying areas, they came across situations when the response given for the number of children in the household was inaccurate because the carer did not wish to reveal the presence of the disabled child. Consequently, it was only after chatting with neighbours did the situation come to light. A more extreme situation was finding the disabled child hidden away from shame. However, the group generally agreed this was rare in the community although cases had been seen. It was felt that in all situations the carers of disabled children need help and support because many of them still feel it (the disability) is the result of a curse due to a past life sin.

b) At the level of the Community

The information regarding acceptance of disability at the community level is contradictory. On the one hand the group states there is no discrimination towards disabled people. However, they go on to say that some people do behave badly towards disabled children in the area. Acceptance, in part, may be related to the type of disability. For example, one woman states that disabled children who can walk do go out and play with peers. However, those that are unable to walk stay at home without company. It was felt that children with polio (post-polio syndrome) are more easily accepted in the community compared to children with other disabilities. This is also the case with hearing impaired children who can communicate with gestures and signals. In contrast, children who have difficulty communicating, (e.g. unable to speak), or looked less normal, (e.g. those that drooled a lot), are called names. The ideas of survival and basic independence play a role in acceptance. For example, one woman states that “...*person cannot move at all. The parents must do everything for him on the bed itself...*”

Daily survival as a key issue in acceptance is mentioned throughout the focus group. There is no time to focus on the disability. It is not observed in the community that the carers of disabled children are any more isolated than the carers of the non-disabled children. Neighbours and relatives are only able help if they have time.

Food and Nutrition

The themes of lack of time and survival continue when the discussion turns to food and nutrition. With regards to disability, the group mentioned they felt the children who had feeding difficulties appeared more malnourished than the other children. The situation was made worse because both parents were often working stating, *"there just is not enough time to sit and patiently feed the disabled child."* The children may be dependent on equally young siblings. One participant states, *"Some children with feeding difficulties are left at the mercy of their siblings."* With respect to providing food, it was felt that it was not particularly harder for families with disabled children than those without. A general comment made was people in Dharavi are all so poor that there is a problem for some to receive one meal a day. The group further emphasises this point when they state that people in the area *"earn enough to feed the children and at times the women do not get enough to eat after the whole family is fed."* The choice factor is not an issue. People simply provide the meals that can be afforded, whether that is *"dahl and rice"* or *"only vada pav"* (gram flour dumplings). The poverty is the limiting factor to food provision and not the disability.

With regards to nutritional value of food the group felt that people in the community are aware for example that vegetables are nutritious, but are not affordable on a daily basis and the quality of most food provided is lacking. However, knowledge without support is useless. The community does not have the means to apply nutritional choice. The community would benefit from nutritional services, including services that provided the nutritional needs for disabled children.

Services and Needs

The group felt that as community workers, they were well placed to help carers of disabled children in a supportive role if armed with training. This comment was also related to learning about nutritionally beneficial foods and feeding skills for helping children with feeding difficulties. Some comments reflected common fears of carers with regards to feeding disabled children with feeding difficulties. One participant states, *"She hopes that the child will not choke"*. However, first and foremost, financial support was mentioned for families of disabled children so that the entire child's needs could be met.

Future

An important concern for carers with disabled children was the future care of the child with disabilities after the parents died. Once again, (as with issues of acceptance), the attitudes here were based on the type of disability. Not all disabled children can hope for the same future. One participant says, *"Many of the disabled children will not get married. Most of them may not get good jobs. They will probably be non-productive members of their families."* It was generally felt that in families with many members, those that were economically productive would receive preferential treatment. In the Indian culture boys tend to receive preferential treatment consequently leading one participant to express, *"The disabled girl child will receive very low attention from her parents."*

Box 3.2. Focus group two – carers of children with disabilities in Ambedkar Nagar (8 participants)

One male participant was present, (the brother-in-law of a female participant who felt her language skills in Hindi or Marathi were not adequate). However, the man spoke very little and appeared resistant to join in the discussion, while his sister-in-law did articulate her opinions. The facilitator and the observer agreed that the group opened up more as the session progressed. However, the group preferred to respond to more structured questions (i.e. more probes were required).

One carer was particularly vocal and preferred to lead the discussion to her particular needs and eventually asked us for help seeking medical treatment (cure) for her daughter. The woman appeared highly frustrated by her 13-year-old daughter's mental impairment, (the girl was the only daughter in the family with several sons). The other participants had much younger children with disabilities and were not expressing the same degree of frustration.

Acceptance of Disability

a) At the level of the Carer and Family

Participants were able to describe the disability of their own child. However, there was a lack of understanding about the disability and its causes. One woman described how she was not permitted by her mother-in-law to take the child for immunisation (polio) in her native place. Much of the emphasis of the discussion was on treatment. The disability was described as an illness. "*My child has no strength,*" was a statement used to describe the weakness associated with disability. The carers stated that the doctors explained nothing to them or "*They (the doctors) job you off with excuses...they do not care.*" The carers expressed that a lot of time, effort and money was spent seeking treatment for the disability. Some carers had specifically migrated to the city in search of a treatment. Words like: *worried, helplessness, frustration* and *pain* were used to describe their feelings about the child's disability. Frustration was felt when the child did not respond to treatment, or feeling tired and overworked because the child was not developing normally or was less capable of daily tasks.

b) At the level of the Community

The carers did not feel that the community discriminated against the child with disabilities. They said all the children are important for family and friends saying "*We have brought these children in to the world and must do our best to take care of them.*" The children played together, but sometimes it was dependent upon the disability, e.g. "*It is harder for my child because she does not speak...but she does play.*" There was some difficulty in the community caused by ignorance. For example, the teachers did not understand the difficulties faced by the child and the family. The parents were also concerned about how the child will be treated by the classmates.

The greater discrimination was felt as a consequence of the poverty rather than the disability, *"Because we are poor they treat us like this..."* People were frustrated by the many obstacles present in seeking services and were angry about the system.

Food and Nutrition

The diet was described as monotonous for all the inhabitants of Dharavi. Food that is good for you was regarded as expensive, e.g. *"Meat and eggs."* The daily eaten foods of dahl and rice were also considered to be good food for health. The child with disabilities is thought to need a good diet to become stronger. However, the carer cannot provide special diets because there is no choice except to eat the same as the rest of the family. Some eating difficulties were described, e.g. being unable to eat independently, child's fear of certain foods and also some carers felt that the disabled child appeared less interested in food compared to their siblings.

Services and Needs

The carers said they valued services like education for the disabled child. However, there were too many practical barriers in getting the child to school. Also, learning daily survival skills was more important for the child with disabilities. The carers felt that access to services was not equal for the disabled and non-disabled children. Obtaining basic necessities was the main priority, e.g. water, electricity, sufficient food, etc. *"Nobody has cleaned our area for over 6 months. All our children get sick more often..."*

Future

The immediate future is a pressing concern for the carers. They said, *"First we think our child should get better....learn to eat....learn to speak..."* While the child is impaired thinking of marriage or future employment was not possible. The daily survival of the family took precedence over long term future planning. The future was left to fate. The main concern for the long-term future was the burden of care for children with disabilities as the carers become older or die. One mother summed up her worry, *"She grows older, but more dependent...if there is a cure then there would be no tension, if she died there would be no tension. But it will be like this forever. Her father accepts the situation...but mothers cannot give up..."*

Box 3.3. Focus group three – carers of children with disabilities in Ragiv Gandhi Nagar (5 participants).

The women participating in this discussion were all very chatty. The questions could be asked with fewer probes compared to focus group number two. One woman was particularly articulate and open in expressing her opinions. She was also very playful with her young daughter who was also present during the meeting. There were a lot of emotions at the end of the session when one participant cried a little after talking about her son.

Acceptance of Disability

a) At the level of the Carer and Family

Participants were able to describe the disabilities of their own children. However, they wished to learn more about the condition. There was a delay in obtaining a diagnosis and in understanding the medical terminology. One carer was unaware of immunisation for polio when she lived in the village. The participants had sought medical treatment. A lot of time and money through private clinics had been invested in seeking treatments. Some families had come to the city because they felt that better medicine was available compared to the village. In some cases, a course of treatment was stopped because the child was not improving or because the carer did not have time to return to the clinic for further advice (work for basic necessities had to take priority). Superstitious and religious beliefs about when treatment should be applied had caused some conditions to be aggravated, e.g. *“...leave it all in the hands of Goddess Devi and let the fever come and bring out all of the impurities. Then there is no need for treatment, you see? This is common for more than half the children...but he became weaker and hasn't progressed in learning to walk so much now....”* The concepts of faith, fate and prayer were mentioned frequently. Sadness was expressed when the child did not develop in the usual pattern.

b) At the level of the Community

The participants did not feel that there was discrimination in the larger community. The children did play together, but limitations were noted depending on the type and severity of the disability. However, some carers did describe situations of over-protection of their child. Carers were anxious of allowing the disabled child outside in case he was teased by others, or in case the child faced a problem and could not communicate it clearly to a stranger and in some cases it was because the child was fearful of the neighbourhood sounds and movements. Ignorance in the community was described. An adult who could not understand the child and thought he had been misbehaving beat the child. Some exclusion was described. For example, one child with speech impairments was excluded from school because the teacher felt the child would not be capable of learning anything.

The carers felt that neighbours were sympathetic, but were unable to be supportive in a practical way. Everybody in Dharavi is too busy just trying to earn a daily income, which leaves little time for helping other people. Carers (mothers) who must decide between working outside of the home thus, leaving the child alone or with less

support and staying at home with a poor income make difficult choices. The greater discrimination expressed was due to the poverty. The poverty limited resources and access to services.

Food and Nutrition

Discussion regarding food is limited when there is no choice about what is eaten. People eat whatever is available. The usual foods are dahl, rice and vegetables. Meat was described as a food that was good to eat, but was too expensive. Special food was not prepared for the child with disabilities. One participant said, "*In the village we eat better. We came here for medicines. And he wants food like in the village...but we can't do that here.*" Food was considered important for the disabled child so that they could become stronger. Some carers described that food had to be forced down because the child was sick and refused to eat. One carer said, "*When my child is in pain he doesn't eat...with the treatment he will be better and then he will eat. At the moment he does not understand what is going on.*" The disabled child was described as being less interested in eating compared to the siblings.

Services and Needs

With respect to disability, the carers felt they all needed more knowledge. Things like education were valued, but schools were too far away and it was not practical to take the children. Some had heard of special schools, but again these schools were not seen as accessible. The priority was food and clothes. They also expressed anger at the BMC hospital services, which were not adequate or polite.

Future

The immediate thoughts of carers were with regards to treatment and cure. For example, "*When his foot is better, it will be better...but if he doesn't get better, then what? ...So you think what can we do to make it better quickly.*" The carers' first thoughts were about the child overcoming the impairment. Future options, like marriage, were limited depending on the type and severity of the disability. There was anxiety about the care of the child after the death of the parents.

Box 3.4. Focus group four - carers of children with no disabilities in Ambedkar Nagar (5-6 participants)

A short, but informative meeting attended by female participants.

Acceptance of Disability

a) At the level of the Carer and Family

Participants could only describe a disability if they personally knew a relative or family friend with a disability. Sympathy was expressed for children with disabilities. It was felt that the families with a disabled child had to face more financial pressure because they would have to seek out lots of medical treatment.

b) At the level of the Community

Nobody felt any prejudice towards a family with a disabled child. The children with disabilities were thought not to be isolated in the community. However, only one participant knew or had seen a child with a disability.

Food and Nutrition

Foods like mutton and fish were described as good for you, but too expensive. However, the women went on to state that even the daily foods of dahl and rice were expensive. Yoghurt, a staple part of the diet in the South of India, was too costly for daily consumption also. For those earning a daily wage, it was noted that the majority of the income is spent on food and even this is not always sufficient or of good quality, e.g. *"We all work...there is nothing left to save. And for such little food. Sometimes a child or woman of the house must go without. At times we can't even have all our meals..."* A couple of women said that food supplements (*channa*- chick peas) were given to her children when they were little at the Municipal schools, but this has now stopped.^{3,4} It was felt that families with a disabled child did not struggle any more than families with many children. The financial struggle was present for all the inhabitants of Dharavi.

Services and Needs

The women all wanted better basic amenities in Dharavi, e.g. Schools, bathrooms, drains and adequate water supplies, (with protection from illegal suppliers). Access to services was described as inadequate for all inhabitants, therefore, it was believed that no services existed or were thought of for disabled children.

Future

It was difficult to consider the future when the daily living was such a struggle. Education was valued, but it was not always possible to keep children in school. The need to earn money was urgent, and children would then lose interest in schooling.

^{3,4} The supplements were given as part of an UNICEF project, which has now stopped.

Box 3.5. Focus group five - carers of children with no disabilities in Ragiv Gandhi Nagar (10-15 participants).

This was a very large focus group. Two ladies from focus group number three had returned by invitation of a field worker. These were two of the poorest participants and the field worker wanted them to have more dahl without it appearing to be like charity. Very few probes were needed during this particular discussion.

Acceptance of Disability

a) At the level of the Carer and Family

Two people could describe disabilities they had seen. One lady spoke of her sympathy for a disabled relative, *"He has lots of problems. Even for providing food and drink at home. If we have money spare, we give to him; or if we have any food left over..."* Sympathy was expressed for people with disabilities. *"...We all just take what God gives us and accept the situation. That's all."*

b) At the level of the Community

There was acceptance of disability in the community. Participants gave examples of community helpfulness towards a person with a disability, e.g. *"He (person with a disability) maybe taken ahead in the line like in the doctor's clinic."* Another participant pointed out that all the young children played together including the children with disabilities. Poverty was the greater cause of discrimination in the community. People had to make difficult choices between staying at home to look after the children or working to earn money.

Food and Nutrition

The cost of food was the limiting factor in making choices about the quality and quantity of what was eaten. Fish and Mutton were described as food that was good for you, but rarely eaten. Dahl and rice were eaten daily with the advantage that the dish could be prepared easily once during the day and then reheated, which was important when daily life was so busy. The quality of the food was poor. Families often substituted vegetables with pickles to save money saying, *"At least the stomach is full."* The daily income was spent mostly on food. Participants said the market prices had recently risen, e.g. Rs.10 for a kilo of rice or flour, Rs. 3 for a small quantity of spinach. The vegetable was mixed up with dahl in order to feed the children properly. Missing meals was also normal, *"...Must pack a lunch for those that attend school. I mean if we do not eat lunch...well an adult can manage, but it is harder for a child."* Food supplements were given in some schools, but not any longer.

Children with disabilities were thought to be fine if they could feed themselves otherwise the lack of time prevented complete attention from the carer being given, e.g. *"...If his hands are OK, then it is fine. But otherwise, it can be a problem, because everyone may have to work, there is no choice... so the child will be hungry at home."*

Services and Needs

Basics like clothes, food, adequate water and electricity supplies (free from corruption), toilets (particularly for the women), toys, safer roads and homes, employment and education were all listed as urgently needed. Participants were tired of promises from local politicians: *"They all come here in voting time...!!!"* Participants were particularly unhappy with BMC hospitals saying they preferred private clinics, *"You get pushed around...At least in the private sector you get treated better..."* With respect to disability, participants said that disabled children should have everything, but people had no time in this poverty to look beyond their own situation, *"No one even thinks of those children."*

Future

At present there is little time to think about the long-term future.

The focus group discussions enabled a broader understanding of attitudes towards disability within this population, which may or may not have had an impact upon the nutritional status of the child with disabilities. The review of current literature suggested that one reason children with disabilities may have a poor nutritional status was because of negative attitudes towards disability leading to neglect in the care of the child. The focus group discussions did not confirm this at all among the participants. All children were thought well of and cared for. The attitudes are summarised below:

- Carers were very concerned for their disabled children. They were worried about the development of their child and wished to learn more about the disability. A lack of awareness of disability and a lack of awareness of services contributed to the present limitation in knowledge. For example, children who drooled were described as mentally ill.
- Carers invested a lot of time, energy and money in seeking treatments or cures for the disability. Some actually decided to migrate to the city for the purpose of seeking out medical help for their disabled child, which confirms some of the anecdotal evidence collected during the SES interviews. It would appear that many carers did not know how the disability was caused, and those living in the native or rural areas had little awareness about the benefits of immunisation programmes.

- The disability was described like an illness. Carers kept faith that the child would recover from the disability. The current condition of the child was described as weak or sick. The key point was that the permanence of the disability was not readily accepted.
- A few carers did believe the disability was due to a curse or a past sin. However, there was an acceptance of the situation. Faith also provided a source of hope for carers.
- The carers of children with no disabilities expressed sympathy for those families with a disabled child. However, no one could really describe a disability unless they had a relative or family friend with a disability. It was not noticed in an area where everybody was too busy with his or her own life situations.
- Nobody stated any discrimination towards children with disabilities within the community. However, examples of ignorant attitudes were given, e.g. a child with speech and learning difficulties was beaten up by an adult who had misunderstood him; a child with communication difficulties was excluded from school because the teacher did not feel he could learn anything.
- Neighbours, although sympathetic, did not have time to be of practical support. This confirms the anecdotal evidence collected during the SES interviews about missing support that was available in the native places of migrants.
- Field workers discussed cases of shame due to disability. However, such situations were infrequent. Generally, the carers of children with disabilities had a tendency to be over-protective of their child.
- Attitudes of acceptance and practical integration were dependent upon the type and severity of the disability. The main limitation for support and understanding was the poverty. The level of poverty was discussed in the focus groups and also confirmed in the SES interviews, which revealed low prevalence of literacy and majority of employment in the unskilled labourer's category. The poverty can be described as the disabling factor for all the inhabitants. Families with disabled adults less able to earn money were in difficult situations. For families with disabled children money was needed for medicines, but it was thought to be no tougher than if one had a large family to provide for. Participants felt difficult choices between time given for care and time taken to earn money did impact on

the children. Those with dependent disabilities were vulnerable in such situations, but there could be no solution.

Some of these attitudes may impact upon the nutritional status of the child. Nobody had sufficient food:

- The daily diet was monotonous, usually dahl and rice. It was of small quantity and poor quality. Foods like meat were frequently described as good for health, but were not affordable.
- It was common for meals to be missed by members of the family, (usually the mother or child). Field workers discussed cases of preferential treatment towards the productive family members.
- Food supplements were rarely received.
- Carers were concerned about the eating habits of the disabled child. Food was described as important for gaining strength and getting better. Some feeding difficulties were mentioned, e.g. fear of choking when feeding, refusal to eat, less interest in eating compared to sibling, a dependent feeder would sometimes be left hungry if the carer had to work. A lack of time for adequate care was a topic raised in the discussions.

A lack of money was described as a barrier to eating well for all inhabitants of Dharavi:

- Basic necessities like clean water were needed before people could think about other services in the community. There were poor services for all children and children with disabilities were not thought of at all.
- The immediate future was important for all participants. For carers of disabled children the primary concern for the long term future was the burden of care for their child. The child with disabilities could not be seen as an independent adult.

The provision of adequate food and a healthy diet was an urgent necessity for all carers. The participants all cared for the children with disabilities and accepted that there was a need for a

greater understanding about the disability. At present little information and services are available for disability issues in Dharavi, (also confirmed in the pre-study visits of Dharavi). Providing an understanding of the abilities of the person with disability and accepting the permanence of the disability should be essential components of any rehabilitation programme in Dharavi. At present, there appears to be a lack of such programmes contributing to the lack of awareness of disability among the study population.

They were concerned about the food eaten by the child with disabilities and the effects upon the health of the child. After each discussion, an interest was shown in workshops for learning more about food and nutrition. There was also a feeling of less isolation for the carers of children with disabilities, many of who previously did not know they shared common problems or were not alone. Many of the attitudes were dependent upon the type and severity of the disability.

These attitudes provided key insights in to the planning of the intervention stage of the study and in the analysis of the nutritional comparisons between the disabled cases and the non-disabled controls.

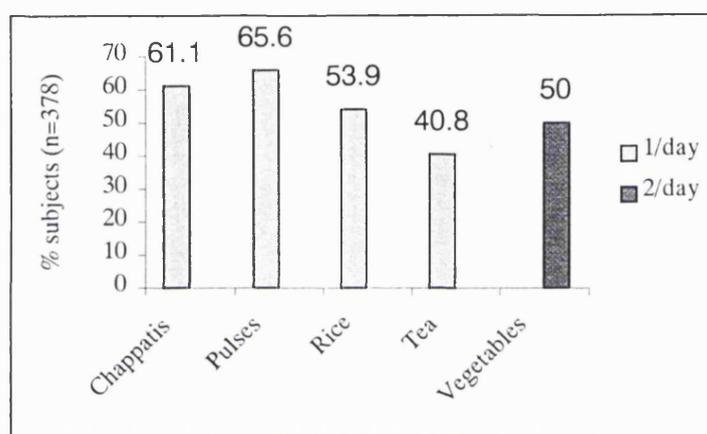
Objective 2: To Compare the Nutritional Status of Disabled Children with their Non-Disabled Siblings and Neighbours & Objective 3: To Investigate Appropriate Measurements of Height in Physically Impaired Children to Facilitate Accurate Nutritional Assessment.

Nutritional comparisons between case and control children were made by investigating dietary intake, anthropometry, micronutrient status and feeding practices. This information composed the baseline survey. Results are collected for all 404 children and there is additional anthropometry data for 21 neighbour children (see Table 3.1, Chapter III, Results, pp130).

1. The Dietary Intake of Subjects

Valid dietary intake information was collected for 378 subjects. The missing data included 13 subjects who were exclusively breastfed, (mainly siblings), and a further 13 where the information was not complete for analysis. (%). Figure 3.10 shows the most common frequently consumed foods (eaten more than rarely/never) for all of the subjects.

Figure 3.10. The most frequently consumed for all of the subjects.



The data collected confirms the findings of the focus group discussions, in which participants described a monotonous daily diet of dahl (pulses), rice, vegetables and chappatis. While this information indicates the foods accessible to the study population, it does not indicate anything of the quantity or quality actually consumed.

Importantly, there were no significant differences between the disabled cases and sibling controls. Therefore, suggesting that no preferential treatment existed within the same household with regards to food given.^{3,5}

^{3,5} However, 4 cases of disabled subjects did have diet intake very different from siblings. This consisted of milk and bread only, or watered down rice only. The carers noted this was the only food that could be forced down. In each case the child was in the neurological impairment group.

Comparing the households with and without disabled children, significant differences were identified between mean frequency intake of meat. Meat intake was consumed greater than the rarely/never category for 25.3% (n=95) of subjects and there was a significantly more (P<0.05) frequent intake in households without a disabled child. Data analysis indicates that 28 disabled cases, 24 sibling controls and 43 neighbour controls consumed meat once a week. The focus group findings revealed meat was considered a food group that was good for health, but expensive and thus, less frequently consumed.

The remaining food that were most likely to be rarely/never consumed by the subjects were: vegetable water (100%), sweet water (99.7%), rice water (99.2%), coconut juice (98.9%), fruit juice (98.4%), dairy products (98.1%), fruit (80.3%), bread (78.4%), eggs (70.4%), milk (72.3%) and fish (53.9).

Additional questions were asked in the survey regarding food supplementation and food preparation (n=404 responses). Carers were asked whether they felt that any food was particularly “good” or “bad” for their child. Only one carer, of a disabled child, responded saying she felt that “cold” food was bad for her child. Carers were also asked whether they ever gave their children something to help them sleep. Only one child (a neurologically impaired child) was sometimes given a tablet to help him sleep by the carer.

21 subjects, (4 disabled cases, 7 sibling controls and 10 neighbour controls) had received nutritional supplements. One child had received a course of micronutrients from the Municipal hospital and the remaining 20 had received food supplements from local pre-schools (ICDS centres). The food supplements were usually *channa* (chickpeas), biscuits or bread. The quality and frequency of the supplements is not known.

There were no significant differences with regards to food preparation between household with a disabled child and those without. For all households, 87.3% use vegetable oil for cooking, which is likely to be provided from the ration shops. The remainder use a mixture of vegetable oil, butter and occasionally ghee. The majority of households use a mixture of aluminium and steel cooking pots (56.2%). A further 23.2% used aluminium pots. 16.5% of

households had access to iron pots. Anecdotal evidence collected during the interview suggested that iron pots were no longer used in the city because they were not fashionable.

The key findings from the investigation of dietary intake show: 1) that there was no preferential treatment with regards to food given within household (between disabled child and siblings); 2) the diet of all subjects was mainly pulses, rice, vegetables and chapatis (in line with focus group findings); 3) the significant difference ($p < 0.05$) in mean frequent intake between households with and without disability was that meat was consumed a little more commonly among neighbour controls; and 4) only 21 subjects (5.2%) had ever received some form of nutritional supplementation.

The dietary intake revealed poor variety of food consumed for all subjects, with few differences between groups. The next stage in analysis compared the anthropometry between groups.

2.1 Correction of Height in Physically Impaired Children for Anthropometric Analysis

A review of the height data entry records from the field indicated that difficulties were encountered in measuring height in approximately a fifth of the disabled subjects (21%, $n=29$). These children were physically impaired classified in either the neurological impairment group (36% of the group) or the motor impairment group (32% of the group). It was possible that the analysis of the inaccurate heights would lead to inaccurate results.

Therefore, these measurements to predict heights were taken: 1) Tibial leg length, 2) Arm length, and 3) Armspan. Table 3.7 presents the records of measurements taken in the field.

Table 3.7. Records of height and height prediction measurements taken in the field.

Measurements	Disabled (n=141)	Siblings (n=122)	Neighbours (n=162)	Total (n=425)
Tibial leg length	140 (1)	116 (8)	161 (1)	417 (8)
Arm length	138 (3)	115 (7)	162 (0)	415 (10)
Armspan	111 (30)	110 (12)	158 (4)	379 (46)
Height	138 (3)	116 (8)	162 (0)	416 (9)

By researcher observation, the most difficult measurement to obtain was the armspan, particularly for the disabled cases. It was not possible for example, if spasticity was present in both arms.

Significant correlations were observed between height and measurements to predict height among the controls. It was decided to derive linear regression equations to predict height using only the neighbour controls because of the specific age and gender matching. The equations are presented in box 3.6.

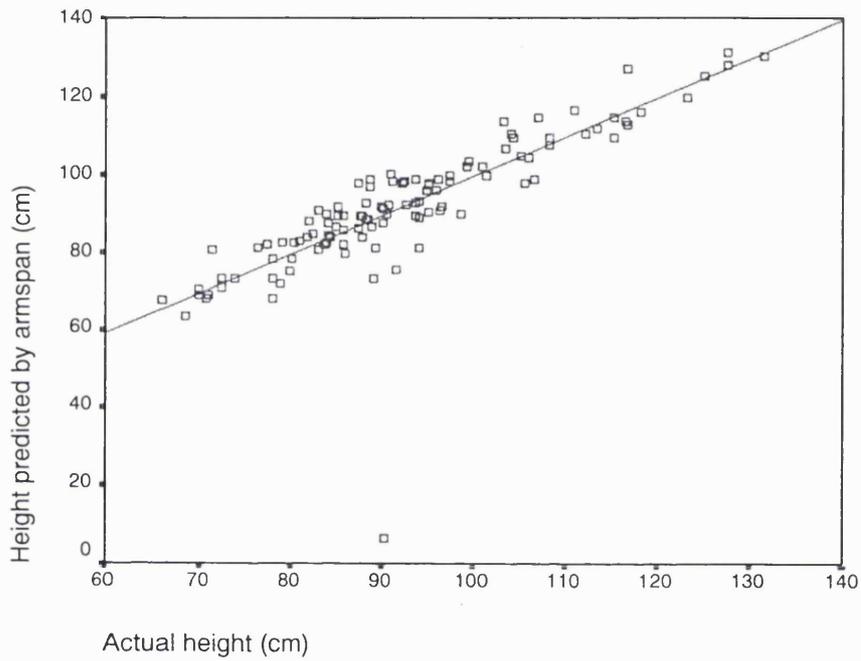
Box 3.6. Linear regression equations to predict height derived from neighbour control subjects.

1. Tibial Leg Length	
• $r = 0.851$ ($p < 0.001$)	
• $\text{Height} = 36.858 + 2.000(\text{Tibial Length}) + 0.307(\text{Age})$	$R^2 = 0.721$
2. Arm Length	
• $r = 0.903$ ($p < 0.001$)	
• $\text{Height} = 27.390 + 1.730(\text{Arm length})$	$R^2 = 0.813$
3. Armspan	
• $r = 0.966$ ($p < 0.001$)	
• $\text{Height} = 6.428 + 0.929(\text{Armspan})$	$R^2 = 0.932$

Predicted heights were calculated from the equations for the subjects with disabilities. Scatter plots of the predicted heights with the actual heights for the subjects with disabilities are shown in figure 3.11.

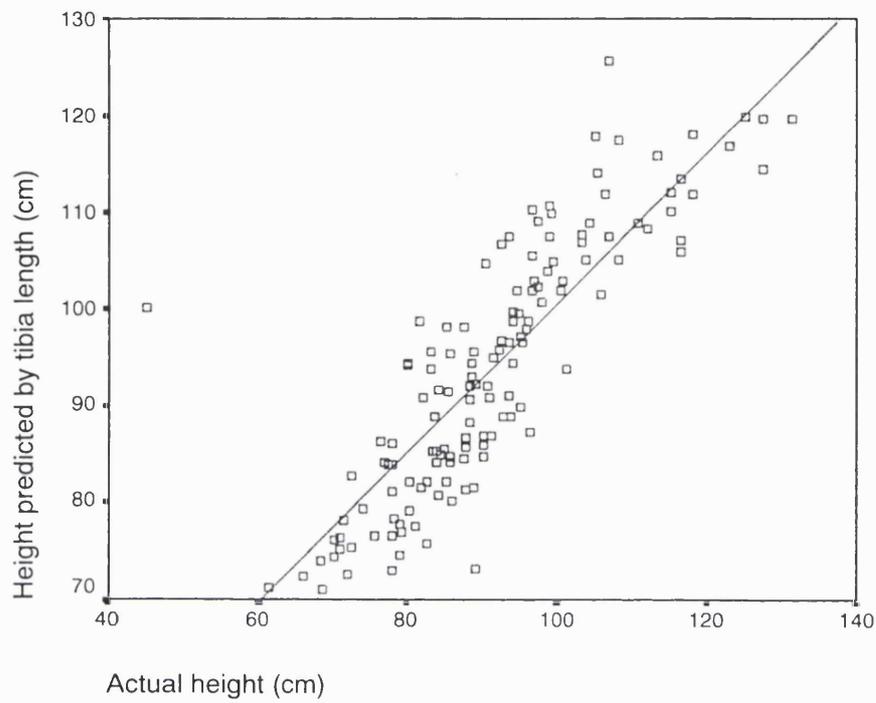
Figure 3.11. Scatter plots of the predicted heights with the actual heights for the subjects with disabilities.

A. Heights predicted from armspan.



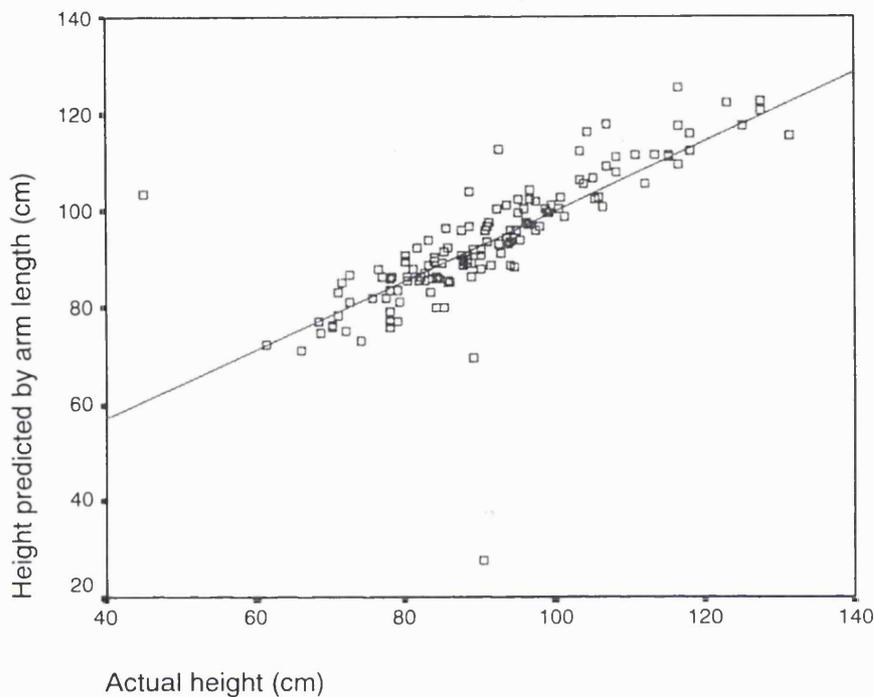
Note: $r = 0.827$, $P < 0.001$, $n = 110$

B. Heights predicted from tibial length.



Note: $r = 0.857$, $P < 0.001$, $n = 137$

C. Heights predicted from arm length.



Note: $r = 0.876$, $P < 0.001$, $n = 136$

All three prediction models, based on the neighbour control population, appear to be useful in predicting accurate height for the disabled case population. The residual models showing the goodness of fit are shown in Appendix 14.

Importantly, no significant differences could be identified by paired t-test between original scores and derived scores with regards to height for the control groups, (after excluding the flagged data).

To summarise all three height predicting measures had good associations with actual height. However, the researcher does acknowledge difficulties with obtaining sufficient armspan data. All of the measurements, when they can be taken accurately do reflect a more accurate description of height/age and weight/height data. In summary, it was possible to overcome limitations in height measurements for children with physical impairments.^{3.6}

^{3.6} It was also noted that weight could not be taken for three disabled cases who were not mobile, but were too heavy to lift. Field friendly methods were not available to overcome this difficulty.

The derived height, height/age data and weight/height results for the 29 disabled cases, where actual height was either not accurate or not possible to take, was entered into the database along with the actual height scores for the remaining subjects. For the derived heights, the first choice was armspan, then armlength and then tibial length (based on the strongest R values) depending on whether the predictive measures were also possible to take accurately. The final database had 396 actual heights entered, 9 heights derived from armspan, 8 heights derived from armlength and 12 heights derived from tibial length. The usefulness of a range of options for deriving height was important in such a study including disabled cases. The analysis could then proceed.

2.2 Anthropometry for Nutritional Assessment

Case-control analysis by analysis of variance (ANOVA) followed by Duncan's multiple range test of the following data were compared between groups: weight/age Z score indicative of under-weight (WAZ), height/age Z score indicative of stunting (HAZ), weight/height Z score indicative of wasting (WHZ), MUAC, TSF and SSF.

The Z scores were calculated using Epi-Nut (version 2.0). Anthropometric data was collected for 425 subjects. A total of 6.8% (n=14 disabled cases, n=13 siblings and n=2 neighbours) records were flagged. Without correcting for height, 8.5% of records were flagged. A flagged record indicates that a measurement may have been incorrectly taken or recorded. Flagged data was excluded during analysis of inter-group comparisons of Z scores.

Summary of Group Anthropometry Comparison

Table 3.8 shows the mean differences in anthropometry measurements between disabled cases, sibling controls and neighbour controls.^{3,7}

^{3,7} Significant differences for sex were checked. In the total population, the sex difference in WHZ was close to significance (P=0.055) and the remaining indices were not affected. Therefore, it was not necessary to control for sex in the data analysis of the three groups.

Table 3.6. The mean (SD) anthropometry results of the case-control groups.^{3,8}

	Disabled (n=141)	Siblings (n=122)	Neighbours (n=162)
WAZ (Z score)	-2.44 (1.39) ^a n=120	-1.70 (1.20) ^b n=109	-1.83 (1.29) ^b n=160
HAZ (Z score)	-2.67 (1.92) ^a n=127	-1.82 (1.87) ^b n=109	-1.74 (1.88) ^b n=160
WHZ (Z score)	-1.27 (1.14) ^a n=124	-0.95 (0.97) ^b n=109	-1.07 (0.88) ^{ab} n=160
MUAC (cm)	14.6(1.8) ^b n=141	15.1 (1.5) ^a n=116	14.9 (1.5) ^{ab} n=161
TSF (mm)	9.2(2.6) ^b n=131	9.6 (2.2) ^{ab} n=109	10.1 (2.4) ^a n=148
SSF (mm)	7.2 (2.2) n=130	7.1 (1.9) n=107	7.2 (1.6) n=149

Note: 1. Mean (SD), Values in row not followed by the same superscript are significantly different (P<0.05) by Duncan's multiple range test.

2. Weight/age (WAZ), height/age (HAZ), weight/age (WHZ), mid-upper arm circumference (MUAC), triceps skinfold (TSF), and subscapular skinfold (SSF).

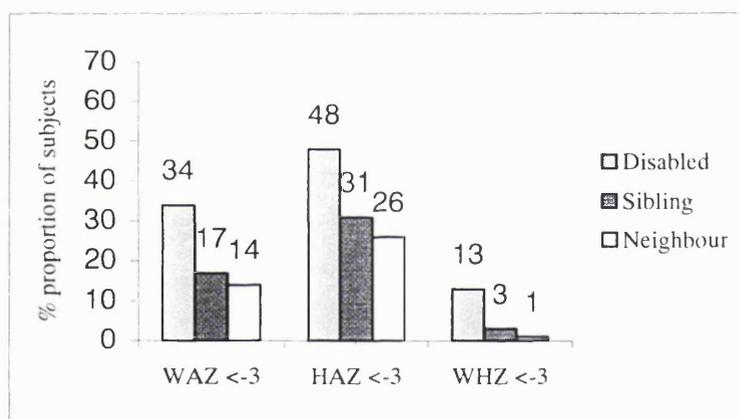
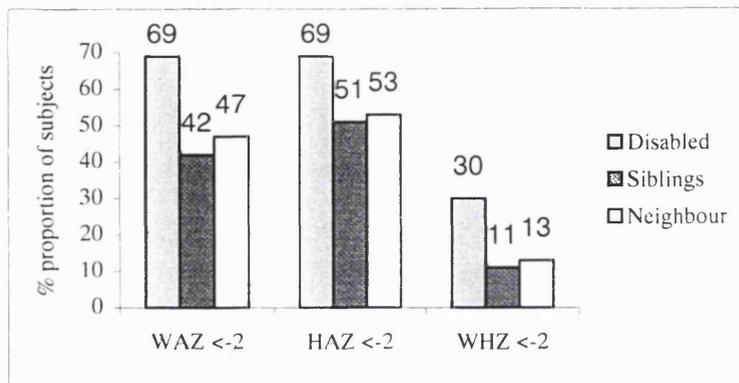
There were no significant differences between the sibling and neighbour controls. This result suggests that the presence of a disabled child in the household was unlikely to have an effect upon the nutritional status of the other siblings.

Significant differences (P<0.05) in the mean anthropometric scores between the disabled cases and the non-disabled controls were identified in the WAZ and HAZ. Further significant differences were identified specifically between the disabled cases and the sibling controls in WHZ and MUAC. TSF was significantly different between the disabled cases and the neighbour controls.

Prevalence of malnutrition by the anthropometric indices was investigated [Figures 3.12].

^{3,8} The result did not differ with the inclusion of the additional 21 neighbour controls.

Figure 3.12. The proportion of subjects with moderate- severe malnutrition (<-2 Z scores) and severe malnutrition (<-3 Z scores).



The prevalence of moderate-severe malnutrition was greater among the disabled group compared to the non-disabled groups in indices of WAZ, HAZ and WHZ. Significant higher proportions of moderate-severe malnutrition for the disabled cases compared with the non-disabled controls were identified in WAZ ($P < 0.001$), HAZ ($P < 0.001$) and WHZ ($P < 0.05$).

The prevalence of severe malnutrition was also greater among the disabled group compared to the non-disabled groups in indices of WAZ, HAZ and WHZ. Significant higher proportions of severe malnutrition for the disabled cases compared with the non-disabled controls were identified in WAZ ($P < 0.05$) and HAZ ($P < 0.05$).

In addition 6% of the total subjects had MUAC cut-off points below 12.5cm indicative of mild-moderate malnutrition. The proportion of disabled cases was higher (12%) compared to sibling (3%) and neighbour (2%) controls; however, there were no significant differences between the proportions of the groups below the cut-off point.

MUAC measurements of some physically impaired children were thought to have reflected increased upper body muscle tone to compensate for an ability to walk (Tompsett *et al*, 1999) thus, the usefulness of skinfold measurement to indicate body fat was investigated. MUAC data correlated significantly ($P<0.001$) with both TSF ($n=387$, $r=0.332$) and SSF ($n=385$, $r=0.416$) by Pearson's correlation coefficient test for total subjects, (within group tests also showed significance at $P<0.05$ value). TSF and SSF data also correlated significantly ($P<0.001$, $n=378$, $r=0.615$) by Pearson's correlation coefficient test for total subjects, (within group tests also showed significance at $P<0.001$ value). Therefore, TSF and SSF were considered useful measurements for the present study.

To conclude, the anthropometric indices of nutritional status revealed that the children with disabilities were more poorly nourished compared with the 2 control groups. Case-control analysis was further conducted by sub-dividing the cases into impairment groups (see Table 3.2, Chapter III, Results, pp 131) in order to investigate the specific impact of impairment upon the nutritional status. It was hypothesised that the impact may vary depending on the type and severity of the disability, (in a similar way that the attitudes towards disability vary according to the type and severity of the impairment, as identified in the focus group findings).

Case-Control Anthropometric Comparisons by Impairment Group

Tables 3.9 a-f summarises the case-control analysis of anthropometry data by impairment group. The specific matched neighbour control for each case child was used. Z scores exclude flagged data.

Table 3.9a. The mean (SD) anthropometry results for the neurological impairment group and controls.

	Disabled (n=55)	Siblings (n=52)	Neighbours (n=55)
WAZ (Z score)	-2.96 (1.15) ^a n=43	-1.88 (1.34) ^b n=50	-2.02 (1.12) ^b n=54
HAZ (Z score)	-3.40 (1.53) ^a n=47	-1.71 (2.14) ^b n=50	-2.11 (1.82) ^b n=54
WHZ (Z score)	-1.34 (1.44) ^a n=45	-1.18(1.00) ^b n=50	-1.03 (1.00) ^b n=54
MUAC (cm)	14.4 (2.0) ^a n=55	15.0 (1.5) ^{ab} n=52	15.1 (1.3) ^b n=55
TSF (mm)	8.5 (2.9) ^a n=55	9.5 (2.0) ^b n=49	10.4 (2.7) ^b n=53
SSF (mm)	6.8 (2.5) n=51	6.8 (2.1) n=50	7.2 (1.6) n=53

Note: 1. Mean (SD)

2. Values in row not followed by the same superscript are significantly different ($p<0.05$) by Duncan's multiple range test.

3. Weight/age (WAZ), height/age (HAZ), weight/age (WHZ, mid-upper arm circumference (MUAC), Triceps skinfold (TSF), and subscapular skinfold (SSF).

Table 3.9b. The mean (SD) anthropometry results for the motor impairment group and controls.

	Disabled (n=28)	Siblings (n=19)	Neighbours (n=28)
WAZ (Z score)	-2.73 (0.83) ^a n=25	-2.00 (1.22) ^b n=17	-1.72 (1.33) ^b n=28
HAZ (Z score)	-2.73 (1.21) ^a n=27	-2.46 (1.16) ^{ab} n=17	-1.69 (2.24) ^b n=28
WHZ (Z score)	-1.54 (0.79) ^a n=26	-0.72 (1.33) ^b n=17	-0.91 (0.62) ^b n=28
MUAC (cm)	14.1 (1.2) ^a n=28	15.1 (1.9) ^b n=19	14.9 (1.3) ^{ab} n=28
TSF (mm)	9.3 (1.9) n=28	9.8 (2.9) n=17	10.2 (2.5) n=28
SSF (mm)	7.1 (1.5) n=28	7.1 (1.6) n=16	7.3 (1.8) n=28

Note: 1. Mean (SD)

2. Values in row not followed by the same superscript are significantly different ($p<0.05$) by Duncan's multiple range test.

3. Weight/age (WAZ), height/age (HAZ), weight/age (WHZ, mid-upper arm circumference (MUAC), Triceps skinfold (TSF), and subscapular skinfold (SSF)..

Table 3.9c. The mean (SD) anthropometry results for the speech impairment group and controls.

	Disabled (n=23)		Siblings (n=20)		Neighbours (n=23)	
WAZ (Z score)	-1.39 (1.64)	n=21	-1.58 (0.57)	n=14	-1.59 (1.94)	n=22
HAZ (Z score)	-1.3 (2.5)	n=21	-1.50 (1.24)	n=14	-1.41 (1.71)	n=22
WHZ (Z score)	-0.87 (0.81)	n=21	-0.85 (0.63)	n=14	-1.11 (1.17)	n=22
MUAC (cm)	15.5 (1.4)	n=22	15.1 (1.0)	n=15	15.2 (2.4)	n=22
TSF (mm)	10.9 (2.3) ^a	n=18	8.7 (2.2) ^b	n=13	10.4 (1.8) ^a	n=19
SSF (mm)	7.7 (1.8)	n=19	6.7 (0.73)	n=13	7.5 (1.4)	n=20

Note: 1. Mean (SD)

2. Values in row not followed by the same superscript are significantly different ($p < 0.05$) by Duncan's multiple range test.
3. Weight/age (WAZ), height/age (HAZ), weight/age (WHZ), mid-upper arm circumference (MUAC), Triceps skinfold (TSF), and subscapular skinfold (SSF).

Table 3.9d. The mean (SD) anthropometry results for the sensory impairment group and controls.

	Disabled (n=17)		Siblings (n=16)		Neighbours (n=17)	
WAZ (Z score)	-2.19 (1.37)	n=17	-1.68 (1.36)	n=16	-1.62 (1.07)	n=17
HAZ (Z score)	-2.40 (2.26)	n=17	-2.00 (2.09)	n=16	-1.16 (1.60)	n=17
WHZ (Z score)	-1.17 (0.84)	n=17	-0.71 (1.04)	n=16	-1.20 (0.72)	n=17
MUAC (cm)	14.6 (1.5)	n=17	15.2 (1.3)	n=16	14.9 (0.8)	n=17
TSF (mm)	9.0 (2.5)	n=15	10.5 (2.1)	n=16	9.1 (2.1)	n=16
SSF (mm)	7.5 (1.5) ^a	n=16	8.0 (2.1) ^a	n=16	6.3 (1.4) ^b	n=16

Note: 1. Mean (SD)

2. Values in row not followed by the same superscript are significantly different ($p < 0.05$) by Duncan's multiple range test.
3. Weight/age (WAZ), height/age (HAZ), weight/age (WHZ), mid-upper arm circumference (MUAC), Triceps skinfold (TSF), and subscapular skinfold (SSF).

Table 3.9e. The mean (SD) anthropometry results for the learning capacity impairment group and controls.

	Disabled (n=14)		Siblings (n=11)		Neighbours (n=14)	
WAZ (Z score)	-1.98 (1.75)	n=11	-1.67 (1.09)	n=10	-1.82 (1.02)	n=14
HAZ (Z score)	-2.26 (2.08)	n=11	-1.57 (2.05)	n=10	-1.58 (1.6)	n=14
WHZ (Z score)	-0.99 (1.33)	n=11	-0.97 (0.72)	n=10	-1.21 (0.68)	n=14
MUAC (cm)	15.2 (2.7)	n=14	15.2 (1.3)	n=11	15.1 (1.0)	n=14
TSF (mm)	9.4 (2.2)	n=11	9.4 (1.7)	n=11	10.4 (2.6)	n=13
SSF (mm)	8.3 (3.1)	n=12	7.3 (1.6)	n=10	7.6 (1.8)	n=13

Note: 1. Mean (SD)

2. Values in row not followed by the same superscript are significantly different ($p < 0.05$) by Duncan's multiple range test.
3. Weight/age (WAZ), height/age (HAZ), weight/age (WHZ), mid-upper arm circumference (MUAC), Triceps skinfold (TSF), and subscapular skinfold (SSF).

Table 3.9f. The mean (SD) anthropometry results for the epilepsy group and controls.

	Disabled (n=4)		Siblings (n=4)		Neighbours (n=4)	
WAZ (Z score)	-3.03 (0.48)	n=4	-1.41 (0.60)	n=3	-1.81 (1.60)	n=4
HAZ (Z score)	-2.79 (0.24)	n=4	-1.61 (0.71)	n=3	-1.65 (2.63)	n=4
WHZ (Z score)	-1.96 (0.90) ^a	n=4	-0.46 (0.42) ^b	n=3	-1.09 (0.90) ^{ab}	n=4
MUAC (cm)	14.5 (1.0)	n=4	15.1 (1.4)	n=4	14.5 (1.7)	n=4
TSF (mm)	10.0 (3.0)	n=4	10.6 (0.6)	n=4	9.1 (2.2)	n=4
SSF (mm)	6.5 (1.3)	n=4	8.0 (1.7)	n=3	6.2 (1.0)	n=4

Note: 1. Mean (SD)

2. Values in row not followed by the same superscript are significantly different ($p < 0.05$) by Duncan's multiple range test.
3. Weight/age (WAZ), height/age (HAZ), weight/age (WHZ), mid-upper arm circumference (MUAC), Triceps skinfold (TSF), and subscapular skinfold (SSF).

The key results are presented below:

- Children with neurological impairments had significantly lower ($P<0.05$) means than the controls for WAZ, HAZ, WHZ, MUAC and TSF.
- Children with motor impairments had significantly lower ($P<0.05$) means than the controls for WAZ, HAZ, WHZ and MUAC.
- Children with speech impairments appeared to have relatively better mean scores in all anthropometric indices, (except WHZ) of nutritional status compared to the controls, although this was not significant. The case group was significantly higher ($P<0.05$) in TSF compared to the sibling controls.
- Children with sensory impairments did not have significantly lower ($P<0.05$) mean scores of anthropometric indices of nutritional status compared to the control groups. The neighbour controls did have a significantly lower ($P<0.05$) mean result for SSF compared to the other study groups.
- Children with learning impairments appeared not to be significantly different in the anthropometric indices of nutritional status compared to the controls.
- Children with epilepsy had mean WAZ, HAZ and WHZ results in the moderate-severe range, while the control groups' results were above the cut-off point. The case children had significantly lower ($P<0.05$) mean than the siblings in WHZ. However, the number of children in each group was 4 and the siblings were in a lower age range group.

From these data, the impairment groups that appeared to be vulnerable to poorer nutritional status as indicated by the anthropometry were the neurologically impaired and the motor impaired cases. The sample size may have produced a lack of significant trends in some other impairment groups, for example, the subjects with learning impairments.^{3,9}

^{3,9} The anthropometric data was also analysed without correcting for inaccurate heights. Mean HAZ was slightly lower and mean WHZ was slightly higher. However, the significant differences identified between the groups did not differ except for the neurological impairment group when mean WHZ was close to being significantly lower than controls without correcting for height, but with corrections was found to be actually significantly lower.

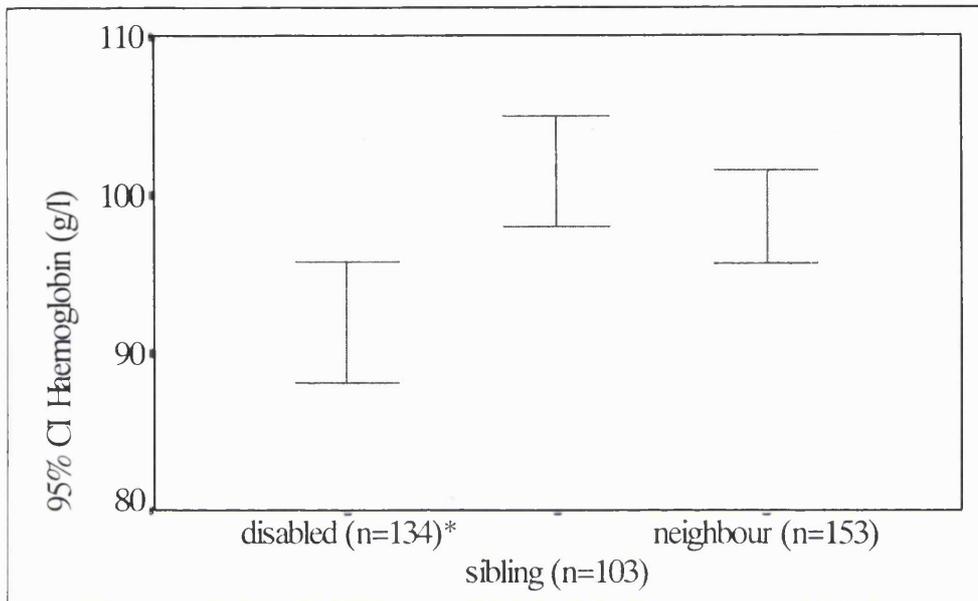
Further analysis was conducted to determine whether any vulnerability to poor nutritional status was seen from the micronutrient data.

3. The Analysis of Micronutrients and Acute Phase Proteins

Summary of Haemoglobin Data

Haemoglobin was measured in the field as an indicator of anaemia (cut-off below 110g/l indicative of deficiency in children, WHO criteria). There was a 92% compliance rate to take haemoglobin measurements from the study population. Figure 3.13 shows the group results for the subjects.

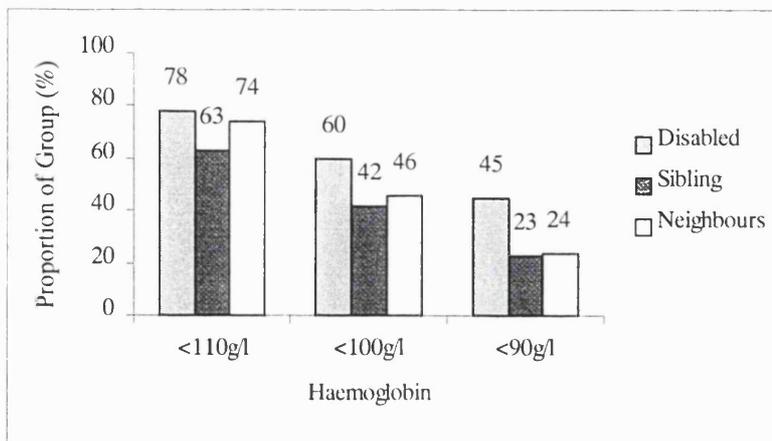
Figure 3.13. The haemoglobin results and 95% confidence intervals for the 3 study groups.



Note: * The mean (SD) result for the disabled case group [92g/l (SD23)] was significantly lower ($P<0.05$) compared to the sibling control group [102g/l (SD18)] and the neighbour control group [99g/l (SD18)] by Duncan's multiple range test.

The children with disabilities had mean haemoglobin results significantly lower ($P<0.05$) than the control groups. The prevalence of low haemoglobin among the study subjects was generally high. Figure 3.14 shows the proportion of each study group that had haemoglobin levels below different cut-off points.

Figure 3.14. The proportion of subjects with haemoglobin levels indicative of anaemia.



There were no significant differences between the means of the sibling and neighbour control groups. The children with disabilities had significantly higher proportions ($P<0.05$) than the control groups below each cut-off point. Subsequently, each impairment group was investigated separately with their specific matched control groups. The results are shown in table 3.10.

Table 3.10. The mean (SD) haemoglobin (g/l) results for each impairment group with matched controls.

Group	Disabled Haemoglobin Mean (g/l) (SD)	Sibling Haemoglobin Mean (g/l) (SD)	Neighbour Haemoglobin Mean (g/l) (SD)
Neurological Impairments	91 (25) ^a n=55	102 (18) ^b n=48	101 (17) ^b n=55
Motor Impairments	98 (20) n=25	97 (19) n=17	94 (24) n=28
Speech Impairments	95 (14) n=21	102 (19) n=13	102 (16) n=21
Sensory Impairments	90 (23) n=17	101 (15) n=15	90 (18) n=16
Learning Capacity Impairments	82 (27) ^a n= 13	102 (18) ^b n=9	97 (18) ^b n=14
Epilepsy	93 (15) n=4	90 (16) n=2	100 (18) n=4

Note: Mean (SD)

Values in row not followed by the same superscript are significantly different ($P<0.05$) by Duncan's multiple range test.

Children with neurological and learning capacity impairments had significantly lower ($P<0.05$) haemoglobin means than their matched control groups. The pattern was similar across the other groups, but lack of significant trends may in part be related to the small sample sizes. The children with motor impairments were an exception, being the only group to have higher haemoglobin mean values than their neighbour controls; however, the difference was not significant.

These data were then further investigated in line with the other micronutrient data obtained through laboratory assays.

Summary of Ferritin, Vitamin A, Vitamin D and APP Data

There was a 38% compliance for venous blood collection among the study population. This was lower than the compliance for haemoglobin analysis, partly due to local fears and superstitions surrounding blood collections. The sample collections were conducted in private clinics to reduce some local concerns of perceived poorer practices in the Municipal hospitals (see Boxes 3.1-3.5 Focus group findings, Chapter III, Results, pp145-152). It is important to note that the sample size number required to identify significant differences fell far short of the required number (see Chapter III, Results, pp130). Appendix 11 summarise the distribution data for the total study subjects for ferritin, vitamin A, vitamin D, CRP and ACT.

The overall results indicated low micronutrient status across the population, which may have been expected from the limited dietary intakes results. Table 3.11 shows the prevalence of micronutrients below the cut-off points indicative of deficiencies.

Table 3.11. The proportion of each study group that had micronutrient levels below the cut-off points indicative of deficiencies.

	Disabled (%)	Sibling (%)	Neighbour (%)	Total (%)
Ferritin (<10µg/l) n=154	7	12	6	7
Vitamin A (<7µM) n=136	33	48	49	35
Vitamin D (<30nM) n=113	35	28	44	35

Note: n= total number of samples analysed.

In the vitamin D assay 34% of samples were below the RIA assay limit of detection, which was 12.5nM.

Table 3.12 shows the mean results for the micronutrients in each study group.

Table 3.12. The mean ((SD) ferritin, vitamin A and vitamin D results of the case-control groups.

	Disabled		Sibling		Neighbour	
Ferritin (µg/l)	48.2 (27.6)	n=59	48.8 (26.0)	n=41	52.4 (26.8)	n=54
Vitamin A (µM)*	0.8 (0.6, 1.0)	n=54	0.7 (0.6, 0.9)	n=33	0.7 (0.5, 0.8)	n=49
Vitamin D (nM)	42.3 (27.9)	n=43	66.8 (52.4)	n=29	51.2 (47.0)	n=41

Note: Mean (SD)

** Geometric mean (95% CI)*

No significant differences were identified among the groups from the Duncan's multiple range test (ferritin and vitamin A) or from the Kruskai-Wallis one-way non-parametric analysis of variance (vitamin D).

Each impairment group was investigated separately with their specific matched control groups using non-parametric tests because of the non-normal distribution patterns. The only significant difference ($P=0.05$) identified was a lower mean vitamin D value for the neurologically impaired subjects (19.7nM) compared with the sibling controls (31.4nM) and the neighbour controls (23.3nM). It was hypothesised that this may have been because of lower activity time spent outdoors among this group. 76% (n=19) of the total subjects with a neurological impairment disabled spent little or no time outdoors were the neurologically impaired children, but no statistical significance was proven. However, it is difficult to accurately quantitate time spent outdoors/sunlight exposure.

Further correlations among micronutrients and APPs were investigated using Pearson's correlation coefficient test or Spearman's rank correlation where appropriate. Surprisingly, no significant association was observed between the haemoglobin and ferritin in the data. The APP were investigated in association with the micronutrients. A negative significant association was identified between vitamin A and log CRP ($P<0.001$, $r= -0.321$, $n=117$), and between vitamin A with ferritin ($P<0.001$, $r= -0.305$, $n=136$) for total subjects. Group analyses identified a positive significant association between ferritin and log CRP ($P<0.001$,

$r = 0.297$, $n = 53$) for the disabled cases, and a positive significant association between ferritin and ACT ($P < 0.001$, $r = 0.270$, $n = 94$) for the control children.

The inadequate sample size may have affected the analysis of these data. However, some conclusions could still be drawn from the results. The low vitamin A and vitamin D status in the total study population was of concern, thus potentially making children vulnerable to impairment and illness. From these data, vulnerability to low vitamin D status appeared to be the most important difference between the case and control subjects, particularly for the neurologically impaired children.

In the comparisons of nutritional status, differences were identified from anthropometric indices (e.g. WAZ and HAZ) and micronutrient indices (e.g. haemoglobin) between the case and control subjects. The main impairment groups identified as vulnerable compared to the matched controls were the neurological (by anthropometric and micronutrient indicators), motor (by anthropometric indicators) and learning (by micronutrient indicators). Impairment groups were made up of different health conditions and varying severity. Therefore, the risk of inadequate nutritional status cannot be determined by an impairment classification alone. The differences in nutritional status among groups identified could not be explained by the dietary intake alone; thus feeding practices and behaviours of the children with disability were investigated.

4. Feeding Practices and Behaviours [Appendix 12 presents additional supporting data of interest].

The feeding practices and behaviours of the case child were investigated in order to determine any factors that may influence the nutritional status. Box 3.7 provides a descriptive summary of the information collected for the case children ($n = 140$). Data was incomplete for one case child. The respondents were carers who knew the children well.

Box 3.7. Summary of feeding patterns.

- n= 59 (42.2%) of cases required some help with feeding.
 - Of the 59 cases that required help with feeding: 12 were fed lying down.
- n= 76 (54.3%) of cases had some extent of chewing difficulty.
- n= 38 (27.1%) of cases suffered some degree of vomiting at meal times.
- n= 15 (10.7%) of cases ate specially prepared foods, (e.g. liquefied or mashed).
- n= 109 (77.9%) of cases ate the same food as the rest of the family.
- n= 104 (74.3%) of cases had meal times at the same time as other siblings.
- n= 100 (71.4%) of cases took longer to eat their meals than the other children of a similar age.
- n= 76 (54.3%) of cases usually went out to play with peers, and 27.9% (n=39) of cases sometimes went out to play with peers.
- n= 76 (54.3%) of cases required either assistance or had some difficulty in walking.
- n=35 (24.9%) of cases had some movement difficulty in the right arm.
- n=35 (24.8%) of cases had some movement difficulty in the left arm.

Some of the data confirmed comments made by carers in the focus group findings. For example, a) it was not feasible to prepare special foods for children that may require it; b) it was not always possible to spend a lot of time for care of children that may need extra attention; c) feeding difficulties were observed by the carers, but little knowledge existed to overcome difficulties; and d) generally, children did go out to play with others. Such results were also important in the development of Stage 2 of the study.

The results presented in box 3.7 were further investigated to determine whether they had any impact upon the nutritional status of the case child. Children were graded by level of feeding difficulties by weighting the responses to the following questions: 1) Does your child have difficulties in chewing?; 2) Does your child vomit at mealtimes?; and 3) Does your child need help with feeding? Responses were scored as: A lot, Some or Never. The classification is shown in table 3.13.

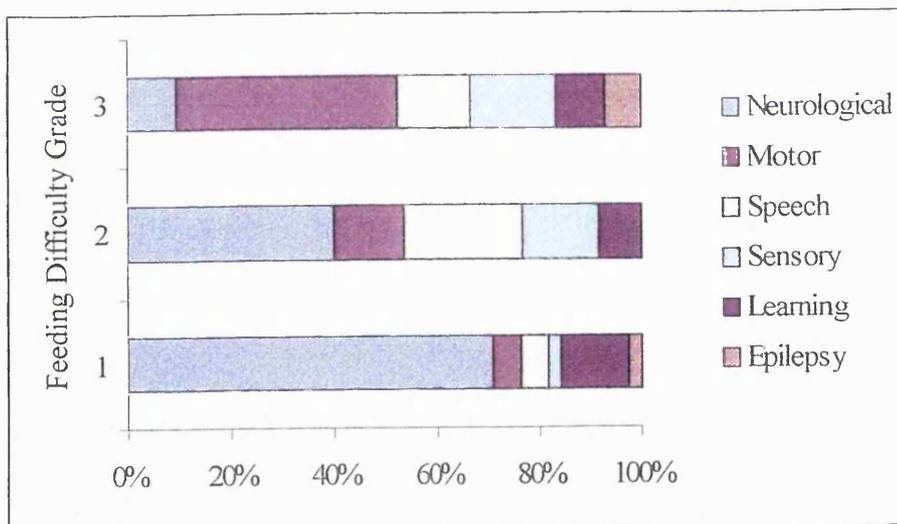
Table 3.13. Classification of feeding difficulties in children with disabilities (n=140).

Feeding Difficulty Grade	Description	No. of Cases (%)
1	Severe	38 (27.1%)
2	Moderate	60 (42.9%)
3	None	42 (30.0%)

Note: Grade 1= 1-3x A lot answers given as a response to feeding difficulty questions; Grade 2= 1-3x Some answers given as a response to feeding difficulty questions; Grade 3= 3x Never answers given as a response to feeding difficulty questions.

The different impairment groups in each feeding difficulty grade are shown in figure 3.15.

Figure 3.15. The impairment groups comprising each feeding difficulty grade.



Feeding difficulty grade 1 (severe) comprised 49.1% (n=27) of the total neurological impaired cases and 35.7% (n= 5) of the total learning capacity impairment cases. Feeding difficulty grade 2 comprised 43.6% (n=24) of the total neurological impaired cases and 63.6% (n=14) cases of the total sensory impairments. Feeding difficulty grade 3 comprised 64.3% (n= 18) of the total number of motor impairment cases.

Each feeding difficulty grade was cross tabulated with the feeding patterns presented in box 3.7. Associations were observed between the feeding difficulty grade and the feeding patterns. However, it was understood that the survey was not accurately able to quantify/measure the responses to feeding patterns perhaps accounting for a lack of significant trends, but the data is presented for interest in Appendix 12. For example, the proportion of children taking longer to eat a meal was more than half of cases in each feeding difficulty grade, (including children with disabilities that were classified as having no feeding difficulties) ($P < 0.01$, $n = 140$, $r = 0.402$).

The carers' perceptions of disability and feeding difficulty were considered important factors in relation to the child's nutritional status. The feeding difficulty grades (as determined by the carers' responses) were then analysed to determine whether they impacted upon nutritional status.

Summary of Risks of Moderate-Severe Malnutrition of Disabled Children with Feeding Difficulties.

The 140 disabled cases with data on feeding practices and behaviours were taken as a cohort group. The risk of malnutrition for children with severe (grade 1) feeding difficulties and moderate (grade 2) feeding difficulties relative to children with no feeding difficulties were calculated. The results are presented in table 3.14. The Relative Risk (RR) and Odds Ratio (OR) formulae are from Kirkwood (1988) and Hennekens and Buring (1987). The results exclude flagged Z scores.

Table 3.14. Relative Risks (RR) of malnutrition of disabled children with severe (grade 1) and moderate (grade 2) feeding difficulties compared to disabled children with no feeding difficulties. ^{3,101}

Nutritional Indices	Severe Feeding Difficulties (Grade 1) RR (95% CI)	Moderate Feeding Difficulties (Grade 2) RR (95% CI)
WAZ (<-2 Z score)	1.1 (1.04-1.14)*	0.9 (0.85-0.95)**
HAZ (<-2 Z score)	1.2 (1.12-1.28)*	0.9 (0.85-0.95)**
WHZ (<-2 Z score)	2.2 (1.40-3.45)*	0.8 (0.74-0.86)**
MUAC (<12.5cm)	2.2 (1.75-2.77)*	1.2 (1.14-1.2)*
Haemoglobin (<110g/l)	1.0 (1.00-1.00)	1.0 (1.02-1.05)
Ferritin (<10g/l)	5.4 (2.28-10.78)*	1.5 (1.31-1.72)*
Vitamin A (0.7µM)	1.2 (1.02-1.41)*	1.6 (1.06-2.41)*
Vitamin D (<30Nm)	1.1 (0.81-1.37)	0.6 (0.37-0.97)**

*Note: *= RR significantly more (P<0.05) likely to malnourished if you have a particular level of feeding difficulty than not.*

***= RR significantly less (P<0.05) likely to malnourished if you have a particular level of feeding difficulty than not.*

(Abbreviations: Weight/age (WAZ), height/age (HAZ), Weight/height (WHZ)).

Table 3.14 indicates the following statistically significant key results:

- Disabled children were 1.1 to 2.2 times more likely to have moderate-severe underweight, stunting, and wasting if a severe feeding difficulty was present than if no feeding difficulty was present. Moderate-severe malnutrition was less likely for children with moderate feeding difficulties.
- Disabled children were 2.2 times more likely to have a MUAC indicative of malnutrition if a severe feeding difficulty was present and 1.1 times more likely to have a MUAC indicative of malnutrition if a moderate feeding difficulty was present than if no feeding difficulties were present.

^{3,101} The X² was calculated with the assumption that expected values would follow the null hypothesis thus, there would be no difference between the feeding difficulty.

- Disabled children were 5.4 times more likely to have ferritin levels indicative of anaemia if a severe feeding difficulty was present and 1.5 times more likely if a moderate feeding difficulty was present than if no feeding difficulties were present.
- Disabled children were 1.2 times more likely to have deficient vitamin A levels if a severe feeding difficulty was present and 1.6 times more likely if a moderate feeding difficulty was present than if no feeding difficulties were present.

Table 3.14 indicates that feeding difficulties, particularly severe feeding difficulties do impact on nutritional status. The risks are significantly reduced for some nutritional indices of children with moderate feeding difficulties. The degree of risk of malnutrition for disabled children with different grades of feeding difficulties compared to matched non-disabled neighbour controls was also calculated by odds ratios [Table 3.15].

Table 3.15. Risks of malnutrition of disabled children categorised by feeding difficulty grade compared to matched non-disabled neighbour controls using odds ratios (OR).

Nutritional Indices	Severe Feeding Difficulties (Grade 1) OR (95% CI)	Moderate Feeding Difficulties (Grade 2) OR (95% CI)	No Feeding Difficulties (Grade 3) OR (95% CI)
WAZ (<-2 Z score)	3.0 (1.13-7.98)*	2.0 (1.05-4.20)*	5.1 (2.05-12.70)*
HAZ (<-2 Z score)	5.3 (1.79-15.70)*	1.4 (1.44-2.83)*	2.3 (1.07-5.65)*
WHZ (<-2 Z score)	5.7 (2.08-15.64)*	1.4 (1.30-1.50)*	6.3 (1.47-27.00)*
MUAC (<12.5cm)	9.6 (1.5-54.86)*	6.6 (1.02-44.39)*	3.0 (2.69-24.19)*
Haemoglobin (<110g/l)	2.1 (1.35-4.10)*	1.8 (1.32-4.27)*	0.4 (0.13-0.83)**

*Note: *= OR significantly more risk (P<0.05).*

***=OR significantly less risk (P<0.05).*

(Abbreviations: Weight/age (WAZ), height/age (HAZ), Weight/height (WHZ)).

Data for micronutrients was not presented because of limitations preventing OR calculations.

The key results presented in table 3.15 are:

- Children with disabilities were more likely to be malnourished than non-disabled control children. This was irrespective of the level of feeding difficulty among the case children. This was true in all nutritional indices, except for risk of low haemoglobin for case children with no feeding difficulty.
- The risk was always greater for case children with severe feeding difficulties than their matched controls compared to the risk for case children with moderate feeding difficulties than their matched controls.
- Feeding difficulty was identified as one reason for poor malnutrition among the case group. However, this did not explain all of the results because case children with no feeding difficulties also had higher risks than their matched controls. In some cases the risks of malnutrition were higher for children with no feeding difficulties than for children with feeding difficulties, notably for WAZ, HAZ and WHZ.

Feeding difficulties, as perceived by the carer, among the disabled cases did impact on the nutritional status of the child. However, the data also identified risks of malnutrition among case children with no feeding difficulties compared to the control group. There are a number of possible reasons that warrant further investigation; e.g. there may have feeding difficulties that were not perceived as such by the carer, and grade 3 case group comprised neurological, learning and a very large group of motor impairments that were earlier identified as being vulnerable to poor nutritional status. Therefore, the full impact of disability on the nutritional status is not yet understood.

A summary of the key results that were presented in objective 2 are listed:

- Dietary intake showed a lack of variety among all study subjects. The significant difference was the intake of meat was greater ($P < 0.05$) among children in households with no disability. However, the focus group findings identified the quality and quantity was poor.

- The nutritional status indices showed a higher prevalence of poorer nutritional status among the case children compared to the control children. This could not be explained by SES factors or by the food frequency data. Also, the care and concern for all subjects was presented as equal in the focus group findings.
- One important factor to impact on nutritional status was feeding difficulties as presented in the current section. Some suggestions of concern for feeding and perceptions of nutrition for the child with disabilities were also revealed in the qualitative focus group findings.

The baseline survey information provided some information for the planning of stage 2. Identification of feeding difficulties as an important factor required more research, however, it was also something that was possible to plan a feasible intervention for based on current knowledge.

Objective 4: To Compare Functional Attainment in the Areas of Motor, Social, Self-help, Cognitive and Language Skills.

Nutritional well-being is associated with other areas of child development. In this study functional attainment was investigated using the Portage checklist. Final scores were obtained using the following equation:

$$\text{(No. of items successfully passed / No. of items tried)} * 100 = \% \text{ of tasks managed.}$$

The results exclude scores for language because the researcher found this was a difficult area to adapt for the cultural setting. Therefore, the results would not be a fair reflection of the children's abilities. The scores for the remaining areas are presented in table 3.16.

Table 3.16. Portage Checklist mean (SD) scores of % of tasks managed for social, self-help, cognitive and motor skills.

	Disabled (n=10)	Siblings (n=10)	Neighbours (n=10)
Social Skills	52.2% (22.5)	72.6% (15.3)	69.8% (13.8)
Self-help Skills	44.2% (19.0)	61.5% (21.5)	56.3% (13.1)
Cognitive Skills	28.5% (20.0)	50.8% (21.1)	49.9% (12.4)
Motor Skills	44.4% (15.0)	54.7% (14.0)	65.1% (12.0)

The results indicated that children with disabilities managed less successful completion of tasks. However, there are several criticisms of the data. Firstly, the group had mixed impairments, which was not accounted for in this small sample. The results provided only a crude measurement, but provided no further useful information to work with. There was no fixed baseline and age was not accounted for, e.g. a child of 3y may have achieved many tasks at the 2y level and scored better than another child of 3y achieving less tasks at the 3y level. In conclusion, the portage was not a suitable tool in this study and could not provide informative and accurate data.

In stage one, the baseline data provided information about the nature of the differences in nutritional status between children with disabilities and controls. Feeding difficulties were identified as a risk factor for poor nutritional status, and feeding skills are also something that can be improved. The results and findings of the baseline survey of stage 1 were then taken forward for stage 2 of the study for the improvement of nutritional status through the improvement of feeding skills.

II. Stage 2: The Improvement of Feeding Practices

The improvement of feeding practices for the disabled cases was based on the findings and results of the baseline survey. The understanding of feeding practices and related behaviours in relation to disability was the key difference identified in stage 1 that an intervention could be planned around. There is sufficient knowledge about overcoming feeding difficulties, which could be applied in an intervention. However, further exploration of the nutritional and feeding problems was necessary for the children with disabilities. Stage 2 of the study only included the disabled case group. A cross-section of subjects were followed from stage 1.

Objective 1: To collect data of detailed feeding practices by researcher observation in order to correlate with the findings of the focus groups in stage 1; and to supplement carer response only based results from the baseline survey.

The primary aim was to collect information that would enable the development of a feasible intervention for the improvement of feeding practices in the home given the scarce resources available for many of the children in the community. Feeding difficulties were graded: 1) by carers through a free response on a Lichter scale, (unlike stage 1, when responses were given to structured questions); 2) by carer response to questions about hunger/thirst of child with disabilities; 3) by researcher observations through a feeding assessment schedule (FAS); and 4) observations of photographs and video films by researcher and independent observers.

1. Observation of Feeding and Nutrition Difficulties.

Nutrition and feeding difficulties data from stage 1 was based on carer response only. The information was not validated by other means. Therefore, a semi-structured questionnaire was designed to investigate further this area by both carer and researcher observation.

55% (n=78) of the 141 disabled cases were surveyed. The mean age of the sub-group was 4.9y (SD 1.8). 39 of the subjects were described as independent feeders by the carer and 39

required help with feeding, (therefore, 2/3 of the original group that required help with feeding were followed up).

Summary of the Extent of Feeding Difficulties.

Carers were asked to determine the level of feeding difficulty they perceived for their child on a 10cm Likert scale, (1cm= severe - 10cm= no problems). Children marked at 1-4cm were classified as having severe feeding difficulties, those marked between 5-8cm were classified as having moderate feeding difficulties, and those marked between 9-10cm were classified as having no feeding difficulties [Table 3.17].

Researcher observations of feeding difficulties used a FAS that looked at the physical aspects of feeding from the child only. Observations were made of solid intake, biting, chewing, drinking and swallowing. Results were weighted between 32-140. Children scoring 32 were classified as having no physical feeding problems, children scoring between 33-54 were classified as having moderate feeding problems, and children scoring more than 55 were classified as having severe feeding difficulties [Table 3.17].

Table 3.17. Level of feeding difficulty by carer’s perceptions and researcher observation.

	Assessed by Carer (n=78)**	Assessed by Researcher (n=77)*
No feeding difficulty	29.5% (n=23)	60.0% (n=46)
Moderate feeding difficulty	38.5% (n=30)	22.0% (n=17)
Severe feeding Difficulty	32.0% (n=25)	18.0% (n=14)

*Note: *= 1 subject could not be observed by researcher because the child refused to eat or drink during the interview.*

***= In the baseline survey, subjects were categorised also by carer response but to specific questions.*

The proportions are similar: No difficulty= 30% (n=42), moderate= 43% (n=60) and severe= 27% (n=38). The mean score was 6cm (SD 3)- Moderate by carer assessment. The mean score was 42.7 (SD 20.0)- Moderate by researcher assessment.

Researcher observation identified approximately twice as many subjects with no feeding difficulties and half the number of children with moderate or severe feeding difficulties

compared to the carers' assessments. However, the difference may in part be explained by the fact that only one meal or snack was observed by the researcher that may not have been a typical experience. Secondly, only the physical process of eating and drinking was observed. The physical difficulties identified for a subject could be overcome by intervention, which is essentially when FAS schedules are designed to be used. However, they only represent one part of the process of feeding. Other factors described in the literature review, e.g. time, carer's attitude and food aversions also play a role in the process.

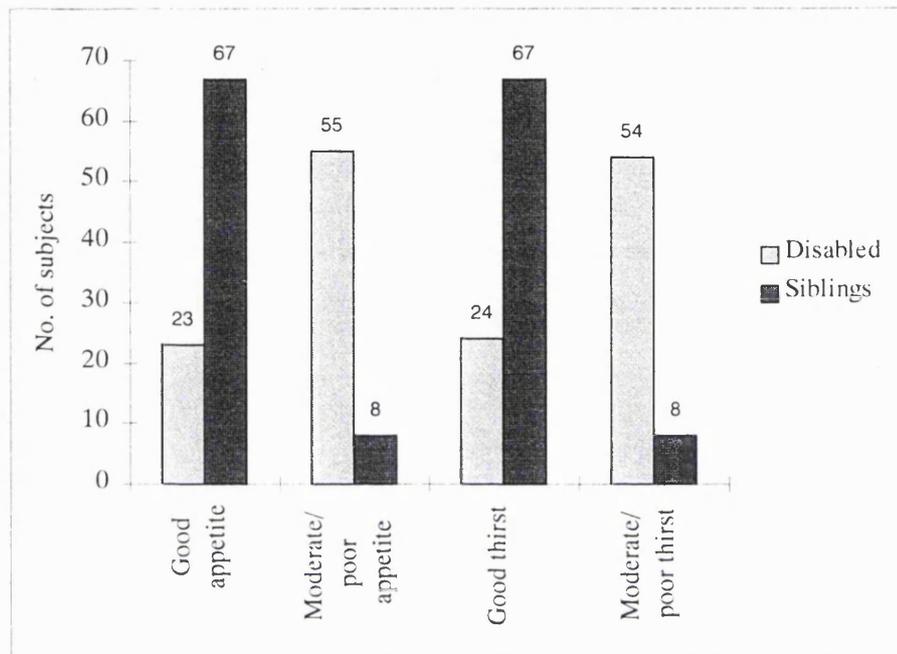
Carer response was likely to have observed a variety of factors over time. The prevalence of severe, moderate and no feeding difficulties was similar to those identified by carer response to structured feeding difficulty questions in the baseline survey which did relate to nutritional status.

The baseline survey identified feeding difficulties as a contributory factor to poor nutrition among the disabled cases. The carer responses to independence of feeding, vomiting frequency and chewing problems were associated with nutritional status. Relative risk analysis indicated that disabled subjects with feeding difficulties were at higher risk of malnutrition. However, it was also observed that disabled subjects with no feeding difficulties were at higher risk of malnutrition than controls. Therefore, the carer may feel other factors play a role in contributing to feeding and nutrition of a disabled child, which have not been embodied in the structured questions or observations.

Appetite and Thirst

The focus group findings revealed that carers felt disabled children were less interested in eating compared with their siblings. The pre-intervention questionnaire asked whether both the disabled child and the sibling had good, moderate or poor appetites/thirst [Figure 3.16].

Figure 3.16. A figure to show the number of disabled subjects and their siblings with good or moderate/poor appetite.



Subjects with disabilities were significantly more likely than siblings to be described as having moderate-poor appetite ($\chi^2 = 56.6, P < 0.001$), and were significantly more likely than siblings to be described as having moderate-poor thirst ($\chi^2 = 54.6, P < 0.001$) in agreement with the focus group findings.

The Time Factor

In the baseline survey, 71.4% of disabled children took longer to eat their meals than their siblings irrespective of feeding difficulty (see Box 3.7, Chapter III, Results, pp180). The focus group findings identified carers as having a lack of time to provide adequate care for their children. The combination of factors may have an impact upon the nutritional status of the disabled child, particularly the dependent feeders. It was important to understand this issue further for the planning of the intervention.

A Likert scale (1cm= long time -10cm= short time) was used for the carer to describe the length of time taken for a disabled subject to complete a meal. Children marked at 1-4cm were classified as taking a long time to complete a meal, those marked between 5-6cm were

classified as taking an expected normal time to complete a meal, and those marked between 7-10cm were classified taking a short time to complete a meal. 67% of subjects took a long time to complete a meal and 18% took a short time to complete a meal. The distribution of cases taking longer and shorter times than the expected normal times to complete a meal were significant ($\chi^2= 38.6, P<0.001$).

For the 39 subjects that required help with feeding, 62% (n=24) carers felt they did not have sufficient time for feeding. The regular feeding responsibility was primarily the mother (n=19) and then grandmother (n=4). However, one-third (n=13) of dependent feeders did not have regular feeder and were fed by any available family member.

In agreement with the baseline survey, the majority of subjects (75.6%) ate at the same time as the siblings (see Box 3.7, Chapter III, Results, pp179). However, 21% of siblings (n=15) were also dependent feeders. Thus, limiting available time for individual attention of the disabled child.

Feeding Position

Feeding position is particularly important for children that require help with feeding by preventing choking/gagging. Good position also improves the swallowing process (Larnert and Ekberg, 1995). In the baseline survey, approximately 1/5 of dependent feeders were fed lying down, which is a potentially dangerous position (see Box 3.7, Chapter III, Results, pp179). Box 3.8 presents some descriptive information on position of the 39 dependent feeders followed up, which provided useful information for the development of the intervention.

Box 3.8. Feeding positions of the 39 dependent feeders followed up.

• Feeding position of child:	6 were fed lying down. 5 were fed in the lap of the carer. 28 were fed sitting up.
• Support:	13 subjects required some support. 26 subjects required no support.
• Position of carer:	34 sat next to or were near to the child during the meal. 3 carers sat opposite (faced) the child during feeding. 2 sat behind the child during feeding

Good feeding position facilitates the feeding process. The descriptive data from the survey provided information for areas of position that required intervention. A photograph was taken with each subject in a typical feeding position (n=65) [Figure 3.17]. Researcher observations of the photographs were used to judge whether intervention was necessary for the improvement of feeding position. This was done after discussion with Dr. Skuse. 15% (n=10) of the photographs showed areas where specific feasible intervention was possible. The information provided an important input for the workshop content.

In summary, the intervention should deal with the physical aspects of feeding, (e.g. position and difficulties with intake and swallowing), and also external factors (e.g. interest in food and time). The researcher observation and judgements were validated by a series of video films of children eating a typical meal or snack.

Figure 3.17. Photographs of subjects in a typical feeding position.

Photographs (clockwise starting from top left): A, B, C and D.



Photographs E and F.



Note:

- A. Child needs to sit up straight, either against carer or wall.*
- B. An example of a good position for both child and carer.*
- C. Child needs to sit up straight and be more comfortable for practical management.*
- D. Child needs to be a little more upright, perhaps better if carer faces child.*
- E. Child needs to be up right and be able to see the food.*
- F. Chin needs to be raised a little for easier intake.*

2. Illustrative Films of Children Eating a Meal or Snack

Additional observational data was provided by films of subjects eating a typical meal or snack. 13% (n=10) subjects were filmed. This method has not been used previously to describe the problems of feeding difficulties faced by children with very little access to professional intervention. Films were used to verify maternal responses on time taken to complete meals of children with cerebral palsy in the UK (Reilly and Skuse, 1992). The films were made to validate researcher observation and confirm the problems described by carers. It was important to ensure that the correct topics were discussed in the workshops. Five objective observers made comments on the films, (4 had professional backgrounds in speech therapy and 1 had a professional background in occupational therapy).

The films were taken as an illustrative examples of feeding practice of disabled children in the area. They contributed towards the planning of the intervention for improving nutritional status and feeding skills. Table 3.18 presents a sample of observations made from the films.

There was general agreement among the observers. The findings identified areas of communication, support, biting difficulties, chewing difficulties, swallowing difficulties, food textures and encouraging independence to be included in the development of the intervention. The development of the intervention should also include cultural appropriateness and awareness. For example, too much conversation during the meal is not appropriate or some carers commented that left handedness (culturally not suitable) was a difficulty in relation to feeding.

Table 3.18.a. Observations of subjects from films by 5 independent observers.

	Subject No.									
	1	2	3	4	5	6	7	8	9	10
Is the child feeding independently?	✓	×	×	✓	×	×	×	✓	✓	✓
Is the child in an appropriate position?	✓	×	×	×	×	✓	✓	✓	×	×
Does the food appear to be specially prepared?	✓ *	✓	✓	×	✓	×	×	×	×	×
Does the child have problems feeding?	×	✓	✓	✓	✓	✓	×	✓	✓	✓
Does the child have problems biting?	×		✓	✓		✓	×	×	✓	×
Does the child have problems chewing?	×		✓	✓		✓	×	×	✓	✓
Does the child have problems drinking?	×	✓	✓		✓		×	×	×	×
Does the child have problems swallowing?	×	✓	✓		✓	✓	×	×	×	×
Does the child have problems coughing/choking?	×	×			✓	✓	×	×	×	×
Does the child dribble excessively?	×		✓		✓		×	×	×	×

Note: Blank box = could not be observed.

**= disagreed on by objective observers. Bread was cut in to bite size pieces, but could not be seen on film.*

Table 3.18.b. Observations of subjects from films by independent observers

Subject No.	Additional Main Comments
1	Requires some help with lip closure.
2	Subject appears to be in some discomfort.
3	Child appears to non-verbally communicate. He appears to be able to grip his hands and sit up if supported, thus, it is possible for subject to be a little more independent. <i>Thicker texture of food may be more appropriate.</i>
4	The food is out of the visual range of the child. <i>The position appears to allow the child independence, but head control is poor.</i> Communication is poor.
5	The child appears distressed during feeding. Communication from the carer is soothing. <i>Thicker texture of food would be more appropriate.</i>
6	Non-verbal communication is used by the subject to indicate wishes.
7	The child is a very slow eater. Hands are able to grip, therefore, may manage some foods independently.
8	An excessive amount of food is taken per mouthful presenting a danger of gagging. Subject may be hypo-sensitive.
9	The position may not be ideal, but does permit independence of feeding.
10	Good example. Perhaps could be encouraged to feed more independently.

Note: Italic script = additional comments made by objective observers.

3. Naturalistic Observations of Shopping Practices and Food Availability in Dharavi

The final pre-intervention data collection for feeding practices was exploring shopping practices and food availability in order to ensure a feasible intervention would be developed. The SES survey from stage 1 identified only 24.6% of families surveyed had stored foods in the home. Therefore, it was likely that shopping was conducted on a daily needs basis, although there was no data to support this suggestion. The dietary intake revealed the typical foods eaten, but no information on the quantity. The focus group findings revealed that much of the household income was spent on food and that it was frequently bought in small quantity with low quality.

Therefore, the data in this section was to supplement the information gathered from the SES data, food frequency and the focus groups from stage 1, and to provide useful information for the planned intervention [Box 3. 9 and Table 3.19].

Box 3.9 A descriptive summary of shopping practices and food availability in Dharavi from naturalistic observations.

Dharavi has one main market area (supplies of kerosene, sugar and salt are usually from here). Kerosene oil is from the ration shop, (e.g. approximately 12kg/family of 7 adults for a week). However, ration shops do not all operate strictly legally and some are supervised by local community groups. Sometimes supplies are delayed and people must queue daily to ensure obtaining a ration.

Many supplies of fruit and vegetables are commonly bought from street side sellers. The prices do not tend to vary from area to area within Dharavi. However, the prices are cheaper here than the other suburbs of Mumbai. The quality is also a little poorer. Fish, (usually dry fish), is frequently sold by door to door salesman during the morning. A little bargaining is possible when buying from street sellers. People tend to ask for a fixed price quantity of food, (e.g. Rs.2/ of spinach), and this quantity of food will be the same everywhere. Women also prepare vegetables (e.g. Shell peas, dry chillies), at a price. The street side sellers tend to wrap up business for the day by mid-afternoon.

Shopping is usually done on a daily needs basis. This is estimated to cost Rs.15-20/ more each month than if food was bought in a larger quantity on a monthly basis (Data from the Preventative and Social Medicine Department, Sion Hospital, Mumbai). Women also tend not to know how to utilise the vegetables they buy to retain the nutrition, or which appropriate vegetables to buy even if all cost a similar amount. It is predominantly women who do the shopping. However, the men will tend to buy the meat.

Table 3.19. Summary of typical prices of common foods within the study area from survey by fieldworkers.

Food Item	Price (Rs)	Comments
Dal: Tuar Masoor Mung	Rs.35-40/kg Rs.35/kg Rs.30-40/kg	<ul style="list-style-type: none"> Commonly buy polished dal. Buy daily. Rs1-2 is sufficient for most families. It can be cheaper to buy mixed dal.
Vegetables	Rs.2-5/	<ul style="list-style-type: none"> Seasonal availability. Buy daily Rs.2 for one bunch of green leaves and up to a max. of Rs.5/ for 3 bunches.
Fruit	Rs.1-2/	<ul style="list-style-type: none"> Seasonal availability. Buy as a treat when it is affordable to family. Rs.1-2/orange, apple, etc.
Coconut	Rs.1-2/piece	<ul style="list-style-type: none"> Tend to buy a whole coconut for religious ceremonies only. Buy now and again.
Rice	Rs.12-18/ 1kg in Ration Shop.	
Flour	Rs.10/ 2kg	<ul style="list-style-type: none"> Wheat is common.
Eggs	Rs.2/ egg	<ul style="list-style-type: none"> Very rare
Milk	Rs.2-5/ 100-150g	<ul style="list-style-type: none"> Not bought daily Tea is frequently drunk black
Bread Rolls	Rs1/ roll Rs. 7/ 8 rolls	<ul style="list-style-type: none"> Usually one per person
Fish	Rs.5-10	<ul style="list-style-type: none"> Women can bargain more here. Tend to buy from door to door type sellers.
Meat	Rs.10/	<ul style="list-style-type: none"> Sufficient for one family meal.

Note: A community health worker for the hospital will receive approximately Rs.450/month, ICDS teacher will receive Rs. 950/month, a daily wage labourer will receive Rs. 50-70/day.

The key points of the pre-intervention data are summarised below:

- The assessment of the degree of feeding difficulty was different between carer and researcher. However, the researcher only considered the physical process of food intake, while the carer was likely to be considering a wider range of factors affecting feeding, (e.g. time taken to feed, prepare food, attention for other siblings, etc.).
- The children with disabilities were significantly ($P<0.001$) more likely to be described as having poor hunger and thirst compared with their siblings.
- Children with disabilities were significantly ($P<0.001$) more likely to take a longer time than the expected norm to complete a meal. Most carers (62%, $n=24$) did not feel they had adequate time to feed their child properly.
- Culturally appropriate interventions for feeding position, eating difficulties, communication, dealing with issues such as constipation/diarrhoea, choking, drooling, encouraging independence and food preparation should be planned.
- Nutritional intervention should maximise upon the limited food affordable to the local population.

Objective 2: To run a suitable intervention and determine carer satisfaction with the intervention undertaken.

The aim was to develop a low cost sustainable intervention that could be used in the future. Workshops were developed with an accompanying manual [Appendix 8]. The advice conveyed during the workshop was targeted to meet the needs of the study population as determined by the collected data. Details of the workshop content are described in the Methods Chapter. The main topics included were: the importance of good feeding skills and nutrition, feeding positions, feeding and drinking skills, encouraging independent feeding, information for children with visual impairments, oral hygiene, cooking demonstration, information on local disability services and useful primary health care services. Photographs taken during the workshops are in Appendix 13.

51% ($n=40$) carers attended the workshops from those participating in stage 2 of the study and 7 requested further home visits. The carers had disabled children with respect to severity

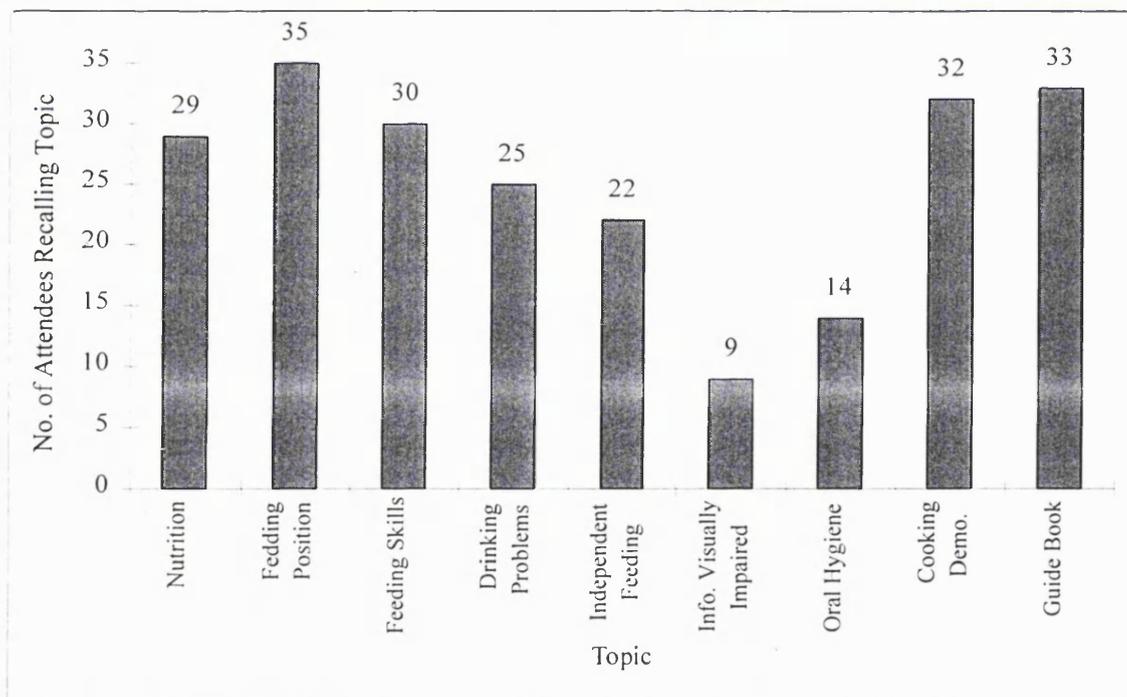
of feeding difficulties. Feedback about the intervention was obtained from 36 of the carers about 1 month later. The aim was to see whether the information was clearly conveyed, easily remembered and practical for the home environment.

1. Carer Satisfaction of Workshops and Manual [Appendix 13: Tables and Figures]

Feedback on Workshops

32 of the carers felt the workshops were held at a suitable time and 30 felt the duration was of suitable length. Carers were asked to recall the topics they remembered from the workshops [Figure 3.18].

Figure 3.16. No. of carers recalling topics from the workshops.



More than 60% of carers recalled most topics. The two exceptions were “Information for visually impaired children” and “Oral hygiene.” These topics may not have been as relevant to the particular group of attendees. Further, all respondents were able to give at least one specific example of a useful piece of information for themselves [Figure 3.19].

Figure 3.19. Examples given by carers of useful things learnt from the workshops.



The examples were classified into 3 categories: 1) 18 examples related to nutritional advice and suitable food preparation for children with eating problems; 2) 19 examples related to helping the child with disabilities to improve eating skills; and 3) 8 examples related to other information (e.g. immunisation, deworming, addresses of local therapy services). 18 carers felt the advice was applicable and 18 felt that some of the advice was applicable to the home environment.

17 of the carers felt they were now more comfortable feeding their child, while 19 felt the same as before. However, 33 carers felt that their children would receive some benefit from the workshops and 2 felt that their children would receive a lot of benefit from the workshop.

Most carers (n=28) did not feel any further information should have been included in the workshops. However, 8 carers did give examples of other topics that included: encouraging children to eat with their right hand, toilet training, reducing diarrhoea episodes, weight gain information and medicine.

Feedback on Workshop Manual

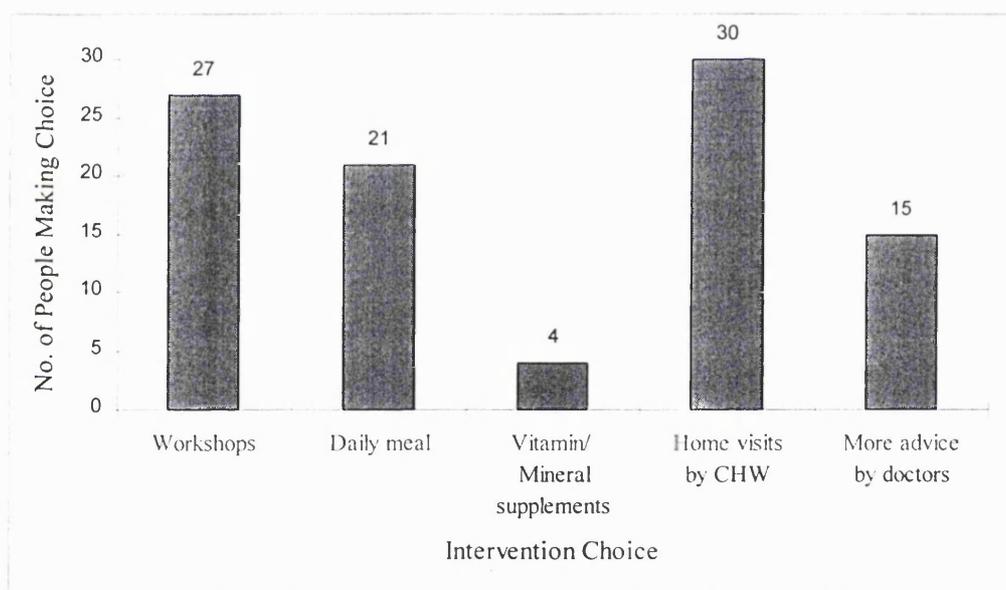
The manual was sometimes used by 12 carers, 14 carers rarely used the manual and 10 never used it one month after the workshops. 34 carers felt the manual was easy to follow. 28 carers

felt the length was appropriate, however, 5 carers felt there should have been more detail included. The manual was written in Hindi which was preferred by 17 carers, but others felt that it would have been preferable to have a copy in Marathi (n=7), Tamil (n=2), other (n=10) (including: Urdu, Gujrati, Karnada). There are many languages spoken in Dharavi reflecting the many states settlers are from. The manual, although mainly pictorial because of limited literacy, did not address the language needs.

Feedback on Future Interventions

Figure 3.20 presents the preferred type of interventions by carer choice.

Figure 3.20. Interventions for nutrition and disability preferred by carers.



Note: Respondents could select more than one choice.

Medical advice and input was seen as important. However, the individual relationship with the community health workers (CHW) was the most popular choice. A course of supplements was not generally considered a preferable option.

25 carers preferred group workshops giving reasons of meeting other people with disabled children and learning from each other (a comment also made after the focus groups of stage 1

of the study). However, 10 carers preferred individual attention. Therefore, a combination of workshops and home visit to address specific needs would be valuable combination for future models of intervention.

To summarise, carers could recall a range of topics discussed in the workshops and give examples of what they found useful, suggesting the content was relevant. The nutritional advice was considered as useful as the advice on developing feeding skills. In the future, other topics should include some additional skills of daily living and understanding disability, (particularly in relation to health seeking guidance). Workshops were a popular intervention choice as well as home visits by CHWs, while vitamin and mineral supplementation proved less popular.

There was positive feed back and many carers felt their children would receive some benefits. However, it was not possible to look at actual change in practice and impacts upon nutritional status. These would be the natural follow up studies.

2. Final Field Team Focus Group [Appendix 10]

To close the study, feedback was obtained from the team of fieldworkers who worked on the project. The aim was to gather feedback on the intervention and also ideas for future programmes on disability and nutrition.

The main questions discussed were:

- Do you feel the workshops were effective in conveying nutrition information for disabled children to the carers?
- Do you feel a disability component should be added in the training of CHWs?
- What kind of sustainable nutrition programme for disabled children is needed in Dharavi?
- What do you think are the priority needs for disabled children and their carers?

A descriptive summary of the discussion is presented in box 3.10.

Box 3.10. A descriptive summary of the final field team focus group.

Six female participants; 4 had been involved in identifying subjects for the study (main experience was CHWs and pre-school teachers) and 2 were CHWs that had attended a workshop. All of the women lived and worked in Dharavi. 2 had previous experience of large-scale nutrition programmes in Dharavi.

Workshops

There was agreement that clear and applicable messages were conveyed in the workshops and manual. Some of the information was important for all of the children in the household, e.g. *“Many people are unaware they have the right to access some treatments for free or just feel they cannot go to Sion (nearby BMC hospital) to ask.”* The workshops also provided an opportunity for carers of children with disabilities to share information with each other.

However, the participants also felt that many carers of more severely disabled children were unable to attend. This was because of either work commitments or because mothers of older children were not able to carry the child to the meeting. It would have been useful to have a workshop for just CHWs because they are in the position to see the mothers all of the time.

Disability Awareness Training

There was agreement that more knowledge about disability would be useful, particularly with regards to feeding. It was considered important because the CHWs know the needs of the local mothers and are more likely than the hospital staff to help. However, the CHWs are poorly paid with lots of work. The amount of training has been reduced over the past few years and they would only receive disability training if a large scale programme was to start in the area.

Nutrition and Disability Programmes

A successful programme would have to be initiated at the government level. The nutrition programmes (and other programmes, e.g. polio camps, ICDS)) that exist are open to children with disabilities. Those that can attend do. The CHWs need a little more knowledge about disability to help more the children they see in these programmes.

Current programmes, mainly ICDS, have over worked staff. The distribution of food is not always fair. The programmes need money to solve the problems and reach all the children. Currently, the CHW knows the disabled children in her area, but cannot visit them all.

Children over 5y need more attention. "... we see the child less in hospital... they are no longer monitored... older disabled children become more isolated. The mother cannot carry the child... at this age the feeding problems get worse." One NGO (Shalom Church) does provide food for deaf children in the area.

A good training programme needs awareness raising about disability in the community.

Priority for Disabled Children

Again awareness of disability was needed. Basic skills were lacking, e.g. feeding skills. Also mentioned was therapy and education.

The team agreed with the carers that the workshops provided clear information. The workshops also met a need in the community because carers did need more information about feeding skills, (this was in agreement with findings of earlier focus groups). However, the team did feel that not all carers were able to attend and that a useful target group would have been the CHWs. The CHWs were invited to the workshops, but perhaps a separate workshop could have been developed. More training for CHWs is valuable, but there are limitations when there is already so much work and little pay.

In agreement with the pre-study visit to Dharavi, programmes do include children with disabilities and those that can attend receive immunisation, nutrition, etc. However, the programmes need further development to reach all children, (including more severely disabled children). Future work should include older children that the CHWs believe are more vulnerable to poor nutrition.

III. Summary of Results for Stage 1 and Stage 2

- 425 subjects were recruited for the case-control study of stage 1 in order to investigate whether the nutritional status of disabled children living in a Mumbai slum (Dharavi) was different from that of non-disabled children.
- The disabled cases were placed in 5 classification groups: 1) Neurological Impairments, 2) Motor Impairments, 3) Speech Impairments, 4) Sensory Impairments, 5) Learning Impairments and 6) Epilepsy.
- No significant differences were identified that could potentially serve as confounding factors in the analysis of the main study objectives.

Stage 2- Objective 1: To understand the knowledge, skills and attitudes of carers towards nutrition, feeding practices and disability.

- The KSA of carers towards nutrition, feeding practices and disability were explored through focus group discussions.
 - Carers were all concerned for the welfare of their disabled child.
 - There was a lack of awareness about disability and available disability services. A lot of time, energy and money was invested in seeking treatments/cures for the disability. The permanence of the disability was not readily accepted.
 - Attitudes of acceptance and integration for an individual with a disability was dependent upon the type and severity of the disability.
 - The daily diet lacked in variety, quality and quantity for all inhabitants. Expensive foods like meats were described as good for you, but not affordable.
 - Carers were concerned about the eating habits of their disabled child.
 - The short term future of the disabled child was the priority for the carers.

Stage 1- Objective 2: To compare the nutritional status of disabled children with their non-

disabled siblings and neighbours.

- A food frequency was used to investigate dietary intake.
 - There was no preferential treatment with regards to food given within the household between the disabled child and young siblings.
 - The diet of all subjects was mainly pulses, rice, vegetables and chapatis, (which was described in the focus group findings).
 - The important significant difference ($P < 0.05$) was the mean frequent intake of meat was higher in control group households than in case-group households.

- Nutritional status between the disabled cases, sibling controls and neighbour controls was investigated by anthropometric indices.
 - There was no significant differences between siblings and neighbour controls suggesting the presence of a disabled child in the household was unlikely to have an effect upon the nutritional status of the other siblings.
 - Significantly lower means ($P < 0.05$) were identified in the disabled cases compared with the control groups for WAZ, HAZ, WHZ (after adjusting heights), and TSF.
 - The prevalence of severe malnutrition was also greater among the disabled group compared to the control groups in indices of WAZ, HAZ and WHZ.
 - TSF and SSF were considered useful measurements of body fat, where MUAC was limited for some children with physical impairments who could potentially have increased upper body muscle tone.

- The differences in nutritional status between disabled and non-disabled children may have been dependent on the type and severity of disability.
 - Children with neurological impairments had significantly lower means ($P < 0.05$) than the controls for WAZ, HAZ, WHZ, MUAC and TSF.
 - Children with motor impairments had significantly lower means ($P < 0.05$) than the controls for WAZ, HAZ, WHZ and MUAC.

- Nutritional status between, disabled cases, sibling controls and neighbour controls was further compared by micronutrient status.
 - The children with disabilities had mean haemoglobin results significantly lower ($P<0.05$) than control groups. Analysis by impairment group showed children with neurological and learning impairments had means significantly lower ($P<0.05$) than their matched control groups.
 - Analysis of ferritin, vitamin A, vitamin D and APP indicated low micronutrient status across the population.
 - Vitamin D was significantly lower ($P<0.05$) for neurological impairment group than controls.

- Impairment groups were made up of different health conditions and varying severity. The differences identified in nutritional could not be explained by the health condition or the dietary intake alone. Therefore, feeding practices and behaviours of the children with disabilities (as suggested in the focus group findings) were investigated.
 - Disabled children were classified into 3 groups: 1) Severe feeding difficulties, 2) Moderate feeding difficulties, and 3) No feeding difficulties. The classifications were based on carer response to specific questions about feeding independence, vomiting frequency and chewing difficulties.
 - Relative risk analysis indicated that disabled children were more likely to have moderate-severe if a severe feeding difficulty was present than if no feeding difficulty was present. Moderate-severe malnutrition was not more likely if moderate feeding difficulties were present.
 - The disabled children were also compared to their matched controls by feeding difficulty. The risk of poor nutrition was always greater for children with severe feeding difficulties than controls compared to the risk for children with moderate feeding difficulties than their controls.
 - However, children with no feeding difficulties also had high risk of malnutrition compared to controls. Therefore, feeding difficulties did impact upon the nutritional status of the disabled child, but this does not explain all of the

differences.

Stage 1- Objective 3: To investigate appropriate measurements of height in physically impaired children to facilitate accurate nutritional assessment.

- It was observed that for children with physical impairments (e.g. kyphosis, scoliosis), data involving height may not be accurate. Therefore, measurements to predict height were also taken.
 - Strong associations between height with: 1) Tibial length ($p < 0.001$, $R = 0.851$); 2) Arm length ($p < 0.001$, $R = 0.903$); and 3) Armspan ($p < 0.001$, $R = 0.966$).
 - Thus, perhaps reflecting a more accurate prevalence of moderate-severe HAZ and WHZ data.

Stage 1- Objective 4: To compare functional attainment in the areas of motor, social, self help, cognitive and language skills.

- Nutritional status is associated with other areas of child development. The portage checklist was not a useful measure in this study.

Stage 2- Objective 1: To collect data of detailed feeding practices by researcher observation in order to correlate with the findings of the focus groups in stage 1, and to supplement carer response only based results from the baseline survey.

- Subjects with disabilities were significantly more likely than siblings to be described as having moderate-poor appetite and thirst.
- The number of disabled children taking an abnormal amount of time to complete a meal than normal was significant ($P < 0.001$).
- Poor feeding position was also an important factor for inclusion in the content of the

workshop intervention.

- Final preparation before the workshop intervention included a study of shopping practices and food availability in Dharavi. Nutritional intervention should account for the limited food affordable to the local population.

Stage 2- Objective 2: To run a suitable intervention and determine carer satisfaction with the intervention undertaken.

- After the intervention period, feedback about the workshops and manual were obtained from the carers and fieldworker team to determine satisfaction about the content.
 - Carer were able to recall the topics discussed in the workshops and give examples of topics they found useful.
 - The nutritional advice was considered as useful as the guidance on developing feeding skills.
 - In the future, other topics for inclusion could be additional skills for daily living (related to feeding) and understanding disability.
 - The fieldworkers also felt that a separate workshop could have been developed for CHWs because they have the best access to all carers of children with disabilities.
 - One key point from the final discussion was that nutrition programmes should consider improving access for disabled children, particularly older disabled children in the future.

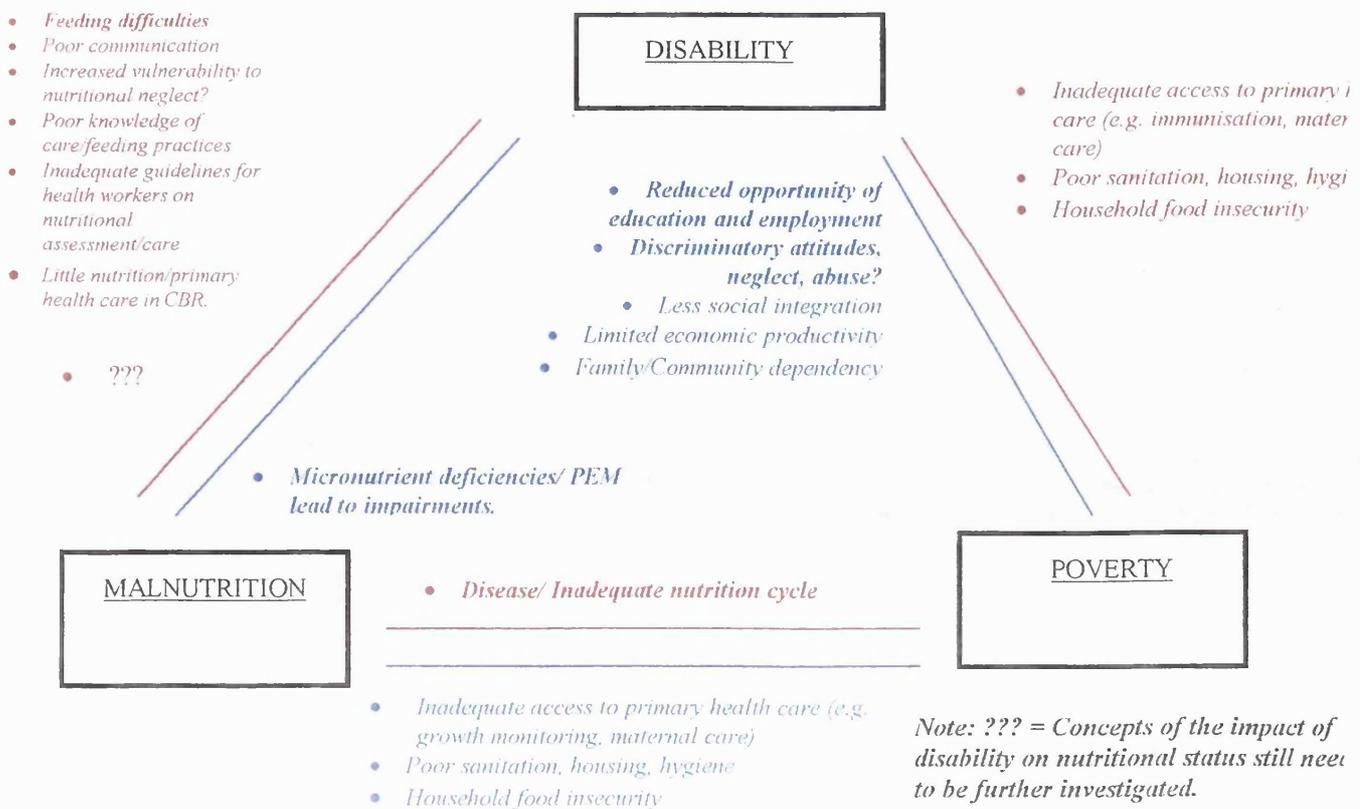
Chapter IV.

Discussion

Vulnerable groups such as women, (especially those of child bearing age), young children, people in emergencies and the elderly, (often with disabilities) are considered important target groups for nutrition programmes worldwide. The literature review presented arguments for the inclusion of disability as another target group for nutrition programmes.

In 1990, the number of people with disabilities in the developing world was estimated to be 184 million (or 4.5% of the total population) (Helander, 1992). While, disability and impairment are recognised as consequences of malnutrition, the vulnerability of children and adults with disabilities is not yet recognised as a potential cause for further malnutrition. There is no consensus on promoting research work on the health of people with disabilities, who may be marginalised and at risk of malnutrition. A possible relationship between disability, malnutrition and poverty derived from the limited evidence in the literature provided an argument for more focus on nutrition and disability in public health [Figure 1.9 is shown again to illustrate this point].

Figure 1.9. "Disability, Poverty and Malnutrition Concept Cycle."



Disability and disease prevention are possible by addressing the underlying causes of malnutrition and inequality. However, those people with permanent disability will remain in the cycle.

The evidence in the literature indicated that undernutrition among children with disabilities did exist. For example, anecdotal evidence suggested that children with disabilities were more likely to be neglected and malnourished, (although, no formal study can confirm such statements). Thomas (1989) found in a UK survey that 40% of young adults with physical impairments were either obese or emaciated, (although, this was only by clinical observations). In general, studies were in agreement that undernutrition existed in disabled populations and feeding difficulties contributed to poor growth (e.g. O'Brien and Whitehouse, 1990; Suzuki *et al*, 1991; Thommessen *et al*, 1991; Dahl and Gebre-Medhin, 1993; Stallings *et al*, 1993; Willig, 1993; Hals *et al* 1996; Ramapge *et al* 1996). However, the majority of studies comprised samples of subjects with severe impairments, who were commonly selected from clinical settings. The studies were mainly of a descriptive nature and there were no major interventions described.

There was a lack of work addressing other topics, (e.g. KSA of carers and food preferences). Work from developing countries was also limited (Tompsett *et al*, 1999; Socrates *et al*; 2000; Pai *et al*, 2001). Anecdotal evidence suggested that in countries where under-five mortality has decreased to less than 20%, for children with disabilities it may still be as high as 80% (Harris-White, 1999) and malnutrition may be a contributory factor. However, the actual extent of the problems and all of the underlying causes has yet to be explored. It is not sufficient to recognise a difference in nutritional status without exploring all the possible reasons to contribute to the differences, (both the external environmental problems and the feeding problems).

We have sufficient knowledge with respect to nutrition to discuss suitable interventions in order to justify screening for disabilities and investigating the nutritional status of children living in poor communities. Hence, it was because of the gap in knowledge regarding nutrition and disability that the present study was

undertaken. The aim was to determine the nature, extent and probable causes of nutritional deficiencies among children with disabilities living in an Indian slum.

The case-control study was undertaken in Dharavi, Mumbai. Dharavi is the largest slum in South Asia. India's current urban growth is paralleled with an increase in the slum population, thus stretching health and education resources (Bose, 1992). This pattern was demonstrated clearly in Dharavi. Consequently, the nutritional status for the whole study population was poor.

425 subjects were recruited for the case-control study. The "Ten Questions Screen" identified the 141 children with disabilities. The screen is limited in detecting mild disabilities, (particularly hearing and visual impairments) (Durkin *et al*, 1995). However, the study was not investigating disability prevalence in the area. The children were recruited through convenience sampling, later evolving through a snowballing effect, and the screen was useful in confirming the suspected disabilities among the cases and confirming lack of risk for serious disabilities among the controls. The impact of known disabilities on nutritional status was being investigated.

I. The Nature, Extent and Probable Causes of Nutritional Deficiencies Among Children with Disabilities.

SES of Study Population

No significant differences in SES were identified between families of the disabled children and their matched controls that could serve as confounders in the analysis of nutritional status. This was in agreement with the previous pilot study in Dharavi (Pai *et al*, 2001).

71% of families were new inhabitants in Dharavi (≤ 10 y), migrating mainly from Uttar Pradesh, (one of the poorest states in India) and Maharashtra, (state of Mumbai). The distribution of religious groups reflected those seen in India. Literacy was low in the area, with only 32% of mothers and 50% of fathers able to read and write. More than

50% of fathers were employed as labourers. The majority of families lived in temporary housing structures with the mean number of people living in a household being 6. The majority of families lived in a nuclear household, frequently leaving the support of the extended family behind in the rural native place.

Disability is often equated with poverty (DFID, 2000). Poverty can be seen as both a cause and a consequence of disability and is also observed as an inequality causing some malnutrition (see Figure 1.9, Chapter IV, Discussion, pp214). It is perceived that families with disabled members in a household may be economically worse off which may impact on nutritional status.

Some trends in the present study did show families with a disabled child to be slightly worse off (e.g. more newer migrants, more illiteracy, larger families, more living in temporary housing, more crowded households, more mothers working outside of the home and more fathers employed as unskilled labourers); however, there was some evidence from the focus group findings to suggest that some very poor families migrated to Dharavi specifically in order to seek help for their child with disabilities. However, the trends were not significant. The study was not designed to specifically investigate the poverty hypothesis. Further, the age group investigated was far below that of economic productivity and therefore, we would not expect to see any real differences in SES between case-control families. Such comments were made in the focus group findings. Poverty was a problem for all families, whether a disabled child was present or not.

Anecdotal evidence and focus group discussions suggested that families with disabled children did spend a lot of time, energy and money seeking treatments and cures. Whether this impacts upon the SES cannot be answered in this study. Tompsett *et al* (1999) suggested that in poorly resourced areas there is little available to actually spend money on the disabled child, therefore, the SES of the family is little affected. This may also be true of an area such as Dharavi. Closer analysis is needed of such factors for households with disabled members because very few studies examine this theory. It may be important for household food security and nutritional status of adults with disability. However, in the present study SES was not a key factor in identifying

and understanding differences in nutritional status between disabled and non-disabled children.

KSA of Carers

Nutritional status is also dependent upon the environmental interactions. For the disabled child, the role of the carer and the social environment may contribute to nutritional health (see Figures 1.4 and 1.5, Chapter I, Literature Review, pp 50). Anecdotal evidence suggests that neglect is a cause of malnutrition among disabled people. The findings of the focus groups did not agree with such a sweeping statement.

In the age group studied, the carers were concerned for the health and welfare of all their children. The disability was commonly described as an illness, which has been observed in other cultures (King and Burgess, 1993). Families spent a lot of time seeking out treatments and cures for the disability. Seeking out treatments for disability, (both traditional and conventional), was also observed in rural Thailand (Pongprapai *et al*, 1996). 33 carers, interviewed in the Thailand study, had invested a lot of time seeking out treatments and information about disability, while the remaining 20 were not able to because of lack of resources in the local area, cost and cultural beliefs. There was a lack of knowledge about disability and a lack of awareness of the few available services in the area among carers in Dharavi also. More basic information about disability was also a priority for families in rural China (Chen and Simeonsson, 1994), a feature of areas with limited available services.

Attitudes of acceptance and integration into the community were dependent upon the type and severity of the disability. This finding is in agreement with studies by Harper *et al* (1995; 1996) that explored attitudes of children towards children with disability in a situation context. The results showed acceptance of the disability was dependent upon both the types of disability and situation.

Some cases of shame or superstition about the disability were described among carers in Dharavi, but such cases were infrequent. Generally, the carers of children with

disabilities had a tendency to be over-protective of their child. The future of the child, for example education, employment and marriage could not be thought about before the learning of daily living skills. This was a source of worry for carers because they could not otherwise see the child as an independent adult. This is in agreement with a child disability and family needs survey conducted in China (Chen and Simeonsson, 1994). The poorer rural families were significantly more ($P < 0.05$) concerned about the long-term future of their children than the wealthier urban families who had more access to information and resources.

The main barrier to providing adequate attention for the care of a child who was dependent on a carer for daily activities was a lack of time and not neglect/abuse. This especially affected children who were dependent feeders. Such external factors have not been adequately investigated in previous studies. Time with respect to feeding has been investigated in one UK study by Reilly and Skuse (1992); maternal stress, not in relation to feeding was investigated in a Bangladeshi study (Mobarak *et al*, 2000); and child behaviour in relation to feeding has also been studied (Richardson, 1988). These studies do show some problems that affect feeding. However, they did not actually measure any quantitative relationship with nutritional status. Other feeding difficulties were described by carers in the focus groups, which could potentially contribute to nutritional status differences.

The diet for all the families was lacking in variety, consisting daily of dahl and rice. It was common for meals to be missed by members of the family, (usually the mother), which was often related to feeding the economically productive members of the households first. Carers, in the focus groups, said that the majority of the family income was spent on food, which is in agreement with the documented literature stating approximately 52% of household income is spent on food in Indian homes (ACC/SCN, 1990).

Basic necessities like clean water were needed for all families. The current services needed to be improved before people could think of specialist services for disabled children. It is clear that one of the complications of studying nutritional status of

disabled children in a developing country is the widespread malnutrition and poverty among the general population. This was agreed in the focus group findings.

The Dietary Intake of Subjects.

The food frequency did not show any preferential treatment in the type of food given to the disabled children and young siblings within the same household. Meat was consumed significantly more frequently by children in households without a disabled child ($P < 0.05$), (43 neighbour children, 28 disabled children and 24 siblings ate meat once a week). Pai *et al* (2001) identified a similar pattern in the pilot study conducted in Dharavi where meat, fish and dairy products were consumed more rarely in households with a disabled child. However, there were no significant differences in nutritional status between neighbour and sibling controls to indicate the impact this difference made. The basic diet for all children was mainly pulses, rice, vegetables and chapatis. 4.1

From the pre-workshop research, quantity and quality of food consumed is poor. The problems of the public food distribution system (ration shops) found in pre-workshop research are acknowledged in the literature (Ahluwalia, 1993). This information was important when the guidelines for the workshop and manual were being planned. It determined the type of nutritional advice that would be feasible. For example, advice on food preparation to minimise nutrient loss was practical or exposure to sunlight for vitamin D rather than advising the consumption of food that was not accessible. No other data was found on the dietary habits of slum populations in India at the time of the present study. Only 5.2% ($n=21$) subjects had ever received any nutritional supplements. In Dharavi, supplements can be currently obtained through ICDS or NGO run pre-school centres and the BMC hospital if a doctor sees the child. However, these services do not reach all children. An important point raised by the final field team focus group was to improve the accessibility of such services to reach all children, particularly older children ($>5y$ of age). Children with severe mobility impairments also find it difficult to reach services, but other children with disabilities do attend. The services cannot

4.1 However, given the feeding difficulties recorded; it may be speculated that differences in intake occur for children with disabilities compared to controls, thus; the disabled child may not be fed to satiety, despite all children being given the same food as found through the qualitative assessment. This may partly explain the quantitative differences identified in the nutritional status between groups.

be described as excluding children with disabilities, but a more concerted effort is necessary to ensure inclusion is achieved.

A World Bank report (Measham and Chatterjee, 1999) stated that India was investing too little in nutrition programmes (including ICDS), despite the fact that 30% of infants are born with low birth weight and more than half the under-fours are malnourished. The report gave recommendations for improvements in ICDS, the public food distribution programme and the national mid-day meals programme. The recommendations were directed to target the most nutritionally vulnerable groups within India.

Nutritional Status: Anthropometry and Micronutrients.

There were no significant differences in nutritional status between the sibling and neighbour controls, suggesting the presence of a disabled child in the household was unlikely to have an effect upon the nutritional status of the other siblings. The result was in agreement with the studies by Tompsett *et al* (1999), Socrates *et al* (2000) and Pai *et al* (2001), which also used sibling and neighbour controls. This is important when determining target populations for child nutrition programmes.

Another important result was that there was no significant difference identified between sexes for any of the case-control groups. This finding was in agreement with other nutrition and disability studies conducted in developing countries (see Tables 1.7.1- 1.7.4, Chapter I, Literature Review, pp67-70). It was a concern because of topics raised in the focus group discussions about family members having to miss meals and preferential attention given at times to more productive members of the household. In studies investigating intra-household intakes, females have been vulnerable to inadequate nutrient intake (Kramer *et al*, 1997). However, the gender bias was not confirmed in the present study.

The disabled case group of the present study had significantly lower means ($P < 0.05$) in WAZ, HAZ, TSF and haemoglobin. The prevalence of severe malnutrition was also

significantly greater in the disabled case group ($P < 0.05$) in WAZ, HAZ, WHZ and haemoglobin compared to controls.

A study in Nigeria demonstrated mild-severe malnutrition by BMI in 13 out of 24 disabled children, however, no matched control group was used (Ojofeitimi, 1983). A second study showed mild malnutrition by BMI among disabled and also in non-disabled children of low SES in a Nigeria (Alakija, 1988).

The anthropometry results of the Dharavi study were in agreement with another Nigerian study conducted by Tompsett *et al* (1999) that found significantly lower means for the mixed disabled cases ($n=112$) in WAZ and HAZ compared to controls (siblings $n=87$ and neighbours $n=112$).

Tompsett *et al* (1999) found that MUAC results were greater for the disabled cases than controls. It was hypothesised that this may partly be because of increased muscle tones in the upper body among children with mobility difficulties who crawled to achieve motility. Therefore, in the present study skinfolds were assessed to counteract this limitation. TSF and SSF were found to be sensitive measures of body fat and could be used where MUAC was felt to be limiting. The mean values of the TSF and SSF fell in the 50th percentile range of American references (Gibson, 1993). The skinfolds were not applied into body fat and body muscle area equations because these have been derived from non-disabled lean adults and would not be accurate for the Dharavi study population (van den Berg-Emons *et al*, 1998). The researcher is aware of the lower accuracy of skinfold measurements for highly obese or emaciated subjects.

Ojofeitimi (1983) suspected 15/24 children to be anaemic, although haemoglobin was not actually measured. Tompsett *et al* (1999) found that haemoglobin mean was significantly higher ($P < 0.05$) for the disabled and sibling subjects (107g/l) compared to controls (101g/l). In the present study, the mean haemoglobin values for all subjects were lower for the Indian population compared to the Nigerian population. Surveys conducted in India between 1977-84 indicated the prevalence of mild-moderate anaemia to be 66% among pre-school children (ACC/SCN, 1991). In the present

study the prevalence of mild-moderate anaemia was >60% for each group, therefore, the results may be expected for an Indian population. The Dharavi pilot study (Pai *et al*, 2001) followed a similar trend. No other study conducted in developing country investigated anaemia.

The case-control micronutrient data is limited by the sample size. Low micronutrient status for ferritin, vitamin A and vitamin D were identified in all three-study groups. Further, only 5.2% of the study population had ever received any type of nutrition supplementation. A significant difference ($P<0.05$) was lower vitamin D status for children with neurological impairments compared to controls. Previous disability and nutrition studies in developing countries have not investigated micronutrient status in children with disabilities

In India, coverage for vitamin A supplementation along with immunisation is improving (ACC/SCN, 1993). However, attention to other micronutrients is also important; 35% of the study population had vitamin D levels below 30nM indicative of deficiency. Vitamin D deficiency may lead to an individual being more susceptible to impairments caused by osteoporosis or rickets. Mughal *et al* (2001) found mean vitamin D levels in 2 year old children living in highly polluted areas of Dehli, India to be significantly lower (31nM, SD17) than in less polluted areas (70nM, SD17). The higher prevalence of bone disorders in Indian cities compared to rural areas was also discussed by Singh *et al* (1992). Children may also cover up more when in the sun because of the cultural preferences for a fairer skin complexion in some parts of India (Singh *et al*, 1992). Dharavi (and Mumbai) are also very polluted perhaps making children more susceptible to deficient vitamin D levels.

Children of Asian origin living in the UK have also been identified as at risk for vitamin D deficiency (Lawson *et al*, 1999). One factor, perhaps applicable to the Indian population was the high content of phytate in chapatis (a regular part of the diet). Although, adequate vitamin D levels can be achieved through sunlight exposure (King and Burgess, 1993), supplements should also be available in areas of high pollution like Dharavi in order to decrease risk to metabolic bone disorders. In the USA, recently the vitamin D recommendation was increased for the elderly population

(Vieth and Carter, 2001), and supplementation programmes in communities like Dharavi should also review vitamin D doses given and ensure targeting of children with neurological impairments. In the future, further studies need to investigate time spent outdoors in detail for this group.

It must also be noted that in the present study, 34% of the samples had vitamin D results below the RIA assay detection limit, perhaps an alternative assay with increased specificity and sensitivity (e.g. HPLC) would have been preferable. However, vitamin D assay technology is still evolving and data must be checked against the results of other laboratories irrespective of assay type chosen (Vieth and Carter, 2001).

In summary, the case-control group analysis showed the disabled subjects did have poorer nutritional status than the control groups. Analysis was conducted by impairment group to determine which conditions were causing the observed differences. Significantly lower means ($P<0.05$) in anthropometric and/or haemoglobin indicators were observed for the neurological impairment group, motor impairment group and learning impairment group compared to controls. Significantly lower means ($P<0.05$) were also observed for vitamin D status in the neurological impairment group compared to controls (discussed earlier).

Children with cerebral palsy and mental retardation (comparable to neurological and learning impairments) had significantly poorer HAZ than Norwegian norms in a Norwegian study conducted by Thommessen *et al* (1991).

Studies on subjects with cerebral palsy have also indicated poorer growth. Krick *et al* (1996) found means Z scores in WAZ, HAZ and WHZ to be at least 1.5SD below the NCHS references for 360 American children with quadriplegic cerebral palsy. A similar finding was observed by Dahl and Gebre-Medhin (1993) on a study with 30 cerebral palsy children. Data from developing countries is limited. Socrates *et al* (2000) found that cerebral palsy children ($n=31$) in the Philippines had significantly lower means in WAZ, HAZ and WHZ compared to siblings and neighbours.

Sensory impairment groups in a study from the Lebanon (n=185) (Shaar *et al*, 1994) and in a study on severe cases in Norway (n=10) (Thommessen *et al*, 1991) have also shown significantly low ($P<0.05$) HAZ data. In the present study, the sensory impairment group (n=17) had the lowest means in nutritional status indicators compared to controls, but the observed differences were not significant. However, the subjects in the Indian data set had mixed levels of severity. It may be worthwhile to conduct further work on this group of subjects.

Micronutrient data, from sub-groups of children with disabilities, from previous studies is limited. Rampage *et al* (1996) conducted biochemical serum analysis from 10 severe cerebral palsy cases. The results were in agreement with the present data from Dharavi with findings of deficiencies in vitamin D as well as other nutrients. Hals *et al* (1996) also noted the importance of improving micronutrient levels in a small intervention study on children with severe cerebral palsy given formula feeds. In the Indian data set, the neurological group was found to spend little time outdoors (76%), but no significant relationship was found between time spent outside and vitamin D level. Previous studies have also observed associations with vitamin D deficiencies and muscle weakness (Rimaniol *et al*, 1994; Grady *et al*, 1991). However, the studies have not focused on neurological cases, but muscle weakness can be observed in some cases of cerebral palsy justifying further research in this area. A difficulty in comparing data with the few other documented studies is the lack of description for with regards to disability classification, e.g. no other information could be found specifically on motor impairment groups. However, in summary, the impairment groups vulnerable to inadequate nutritional status in the present study were: neurological, motor and learning. Future studies should also look more closely at the sensory impairment group.

Feeding Difficulties as a Risk Factor

The impairment groups comprised different health conditions and varying severity. After analysing data on related feeding practices and behaviours, one of the possible factors that explained some of the differences in nutritional status was degree of feeding difficulty.

Feeding difficulties have been documented as a problem for children with disabilities. The focus has been mainly on oral-motor difficulties. The area is important because of the relationship with other areas of child development, e.g. speech development. Feeding problems have been noted in 40-50% of children with cerebral palsy; particularly severe problems exist for quadriplegic cases (Trier and Thomas, 1998). Other researchers have documented similar findings (Reilly and Skuse, 1994; Krick and van Duyn, 1984), but did not correlate with nutritional status.

In the present study, classifications of feeding difficulties (severe, moderate and none) were based on carer response to specific questions about feeding independence, vomiting frequency and degree of chewing difficulty. The severe feeding difficulty group comprised mainly neurological and learning impaired subjects, which were the impairment groups earlier identified as vulnerable to poorer nutritional status compared to controls. The no feeding difficulties group comprised mainly motor impaired children who were earlier identified as having poorer nutritional status by anthropometric measurements alone.

The groups, classified by feeding difficulties, were closely associated with nutritional status data. Subjects with severe feeding difficulties were significantly more likely ($P<0.05$) to be at risk of poorer WAZ, HAZ, WHZ, MUAC, ferritin, vitamin A and vitamin D status than those subjects with no feeding difficulties. The degree of risk was reduced for subjects with moderate feeding difficulties, but still present for MUAC, ferritin and vitamin A, compared subjects with no feeding difficulties.

Similar findings have been documented in 3 previous studies. Children with severe mixed disabilities who had oral-motor dysfunction and impaired self-feeding clinically (which were clinically assessed) were significantly more likely ($P<0.05$) to have lower energy intake than disabled children without these problems. However, energy intake in these studies was estimated by food record diaries kept by carers and no biochemical assays of nutritional status were conducted.

The documented data is limited on mixed disabilities and the focus has been on cerebral palsy. Socartes *et al* (2001) assessed children with cerebral palsy for impaired

self-feeding in the Philippines. The results indicated that WAZ was significantly lower ($P<0.05$) for disabled subjects with impaired self-feeding than those with moderated or no self feeding problems.

Stallings *et al* (1994) identified in a clinical study that children with hemiplegic cerebral palsy were significantly more likely ($P<0.01$) than children with diplegic cerebral palsy to have oral-motor difficulties. However, no difference was found between the nutritional statuses of the two groups. The important point was that the study showed focus of feeding difficulties and nutritional status should not only be on cases of severe quadriplegic cerebral palsy. More studies are needed to investigate feeding difficulties in children with a range of disabilities and a range of severity. Increased risk of poorer nutrition for disabled subjects compared to matched neighbour controls by feeding group was also presented in the Dharavi study. Subjects with severe feeding difficulties had the highest significant ($P<0.05$) risk of poor nutrition compared to controls. However, disabled subjects with no feeding difficulties were also at some risk of poor nutrition compared to controls.

There are a number of possible reasons for malnutrition of disabled children with no feeding difficulties compared to control groups. For example, other feeding difficulties which were not asked about may have been present. This was further investigated by asking carers to determine the level of feeding difficulty they perceived from experience using a Likert scale. The proportions of severe, moderate and no feeding difficulties were similar to earlier responses by carers on specific feeding difficulties.

After further exploration, other feeding problems identified included a perceived lack of appetite and thirst for disabled children compared to sibling controls by carer response ($P<0.001$). This was in agreement with a finding made by Thommessen *et al* (1989) who found all 10 cases studied with congenital severe deaf-blindness were more likely to frequently refuse food than non-disabled children of a similar age. Few other studies have investigated the lack of interest in food by children with disabilities.

The number of disabled children taking an abnormal amount of time to complete a meal was significant ($P < 0.001$). 62% of carers of dependent feeders said they did not feel they had sufficient time to feed their child. The previous studies focus on time taken to complete a meal only for cerebral palsy children (Reilly and Skuse, 1992; Johnson and Dietz, 1985; Gisel and Patrick, 1988). The most important consequence is experience of carer stress affecting feeding management.

Researcher observation of feeding difficulty results using FAS were very different to carer responses. The FAS only recorded the physical problems experienced by the child and did not encompass the full range of problems experienced by carer and child encountered over time during meals.

There is no gold standard FAS. Mostly, these schedules are used in clinical settings to facilitate assessments made by the multidisciplinary team. They accurately show the physical problems that need to be managed to improve feeding, but are only part of a series of interviews and assessments made in the clinical situation. In this study, they highlighted areas of feeding management that could be included in the workshops. However, generally in poor communities, the assessments of feeding difficulties are likely to be made by CHW with little specialist training, unlike health therapists. The combination of carer responses appeared useful in this study for recognising problems in feeding with associations to nutritional status.

Previous studies have tended to only use professional clinical assessments of feeding difficulties (e.g. Thommessen *et al*, 1991; Stallings *et al*, 1994). The accuracy of maternal responses to child illness has been recorded in the literature (Rousham *et al*, 1998). It may be that maternal responses about feeding difficulties of the child are also useful. Although carers may over-report to gain attention for a disabled child, particularly in an otherwise poorly resourced area, it is potentially one method of finding disabled children who are at risk of malnutrition and nutrition related problems.

There may be other factors involved, apart from feeding difficulties, to explain why disabled subjects with no feeding difficulties have worse nutrition than the controls

that were not identified in the present study. In some cases poor growth may a consequence of the aetiology of the health condition/syndrome, e.g. Duchenne Muscular Dystrophy, Down syndrome, (however, optimal nutrition is still necessary to prevent malnutrition causing further impairment and disease).

In a recent study, serum levels of leptin hormone were analysed in a sub-set of samples from the present study. Leptin hormone, secreted from the fat tissues, interacts with insulin and cortisol, controls energy metabolism and is involved in the fasting response.

Leptin levels were significantly higher ($P < 0.05$) in the neurological impaired subjects compared to controls. One explanation is that body fat is frequently high in neurological impaired subjects because of lack of motility leading to increased leptin hormone secretion. The current data showed that children with neurological disability had lower triceps skinfold thickness than the non-disabled children. However, skinfold thickness cannot easily be extrapolated to percent body fat in such a population because in malnourished people fat may be stored around the internal organs in preference to subcutaneous storage and therefore, skinfold thickness may not be indicative of percent body fat in such a population. It may be possible to speculate that leptin is secreted from fat around the internal organs in such cases or it may be related to the control of energy metabolism during starvation (Freeman AC, Yousafzai AK, Filteau SM and Pai M at the Centre for International Child Health, Institute of Child Health and the NCII, Mumbai (2001) *Serum leptin in disabled and non-disabled children in an Indian slum population*, submitted paper).

The main data set also showed significant vitamin D deficiencies in this group potentially leading to muscle weakness and further motility problems that could affect appetite. This work needs much more investigation before conclusions can be drawn, but it may be an example of another affecting nutritional status worth investigating. Subjects with no feeding difficulties also included neurological impairment cases, (as well as speech impaired subjects for whom a more accurate classification into learning or neurological impairment groups could not be made).

Clearly, more work is needed to explain poor growth and nutritional status for children with disabilities. The current information does not provide a complete picture.

II. Interventions and Guidelines for Improving Nutritional Status of Disabled Children in Low-Income Communities.

There was some evidence collected to suggest that some children with disabilities in Dharavi did have an inadequate nutritional status that required attention. The main factor clearly identified in the study, which was contributing to the nutritional status, was feeding difficulty. There is sufficient knowledge about the management of feeding difficulties to justify planning an intervention.

Children with disabilities in higher income communities have access to the specialist services of a multi-disciplinary team in clinics (see Figure 1.7, Chapter I, Literature Review, pp72). In an ideal situation, the therapists work together in a rehabilitation programme that will include the management of eating and drinking difficulties.

Many studies have investigated the advantages of gastrostomies, (e.g. Corwin *et al*, 1996). However, even if this option was available for families in the study setting, it would still only be relevant for a minority of children. There are few studies that have investigated nutrition interventions for children or adults with disabilities using a gastrostomy.

Appropriate dietary planning in an institutional setting for adults with severe developmental disabilities has been investigated (Hogan and Evers, 1997). Dietary guidelines and physical education were recommended after a survey of nutritional status of adolescents with disabilities attending special schools in Tokyo (Suzuki *et al*, 1991). However, no follow up study was conducted to determine if guidelines were implemented and whether they were effective. Other nutrition supplementation studies for children with severe disabilities have been conducted in institutional or clinical settings (Hals *et al*, 1996; Ball *et al*, 1999). However, formula

feeding/supplementation was neither feasible in the present study, nor suitable for all the children.

More practical feeding guidelines have been written for families living in low income communities where there is no access to specialised equipment or services (e.g. *Feeding for the Child with Cerebral Palsy*. The Indian Institute of Cerebral Palsy). The researcher is not aware of any training manuals on feeding management, (mainly found in the grey literature) having been previously evaluated for effectiveness.

The manuals written contain little or no nutritional and other related primary health care advice, which is needed. The carers of disabled children often have little time for other activities in developing countries, therefore are less likely to receive useful health care information that could be beneficial for all the family. The families are living under already difficult circumstances with the burden of daily care usually falling on the mother (Mobarak *et al*, 2000). Observations regarding lack of carer time and lack of knowledge about disability and basic nutrition were also observed in the present study.

Therefore, a culturally appropriate and needs appropriate manual was developed for the study. The manual with workshops (and the option of home visits) comprised the intervention. Information on nutrition, basic health care, disability, as well as feeding management was given.

40 carers attended the workshops. Positive feedback was given regarding content and useful information on what also could have been contained. The feedback on the whole suggested appropriate content, but no other comment can be made about the intervention. The researcher is aware that such an intervention was likely to attract the keenest carers, perhaps with more available time or children with milder feeding and other impairments. This issue was also raised in the final field team focus group discussion (see Box 3.10, Chapter III, Results, pp206].

Future work will need to investigate 3 issues: 1) Is the training package effective in realising actual change of practice in feeding management within the home, (the

package does not assume high literacy in the design) (Azmy M, MSc Dissertation Research in progress, Centre for International Child Health, Institute of Child Health, London, 2001); 2) Does such an intervention have any impact on the nutritional status of the child; and 3) What is the most practical means of application of such a training package and or/other appropriate nutrition intervention in order to meet the needs of a wide range of children with disabilities in the community.

If a useful intervention is proven to be effective in the future, the third issue is challenging from a public health prospective. In Dharavi, there are very few services available for children with disabilities. The existing services (providing education and therapy) are run by local NGOs. Ideally, such services need to be made aware about the value of a nutrition component in their programmes.

Nutrition programmes do exist in Dharavi, e.g. ICDS. However, participation in nutrition and health programmes is dependent on many factors (Carmichael *et al*, 1994). For, the carers of disabled children basis issues like the physical access to a service can become more important. This was also discussed in the final focus group.

ICDS services and the Urban Health Centre (UHC) have trained CHW who are responsible for nutrition, growth monitoring and immunisation and family planning. These women are ideally placed in the community to know the children with moderate-severe disabilities. However, they have no basic training about disability.

The WHO has developed a training package for PHC workers in areas typical of Dharavi, for early identification and intervention of disability (Wirz *et al*, 1999). Such approaches, including basic health care advice, may be a feasible means of approaching nutrition and disability issues.

III. Limitations of Nutrition and Disability Studies

Several unresolved issues were described in the literature review that required attention. A fundamental problem was the appropriateness of standard anthropometric measurements used to assess nutritional status. Thommessen and colleagues (1991)

advised caution when interpreting height data from nutrition and disability studies. Dahl and colleagues (1996) found that 7/35 height data had to be discarded because of lack of reliability.

The problems can be exacerbated in field studies because of a lack of specialised equipment. The UN (1986) guidelines for nutritional surveys need to be updated:

“Do not weigh or measure a child if the child is physically deformed which will interfere with or give an incorrect measurement. To be kind you may want to measure a child and make a note of the deformity on the questionnaire.”

Such guidelines are very inappropriate. Previous studies have investigated alternative measurements that can correlate with height [Table 4.1].

All measurements show strong significant correlations with height. Demi-span was found difficult to take by field workers in the Nigerian study. Researchers also acknowledge difficulties in obtaining accurate armspan measurements, particularly when spasticity or contractures are present in both arms. Taking halfspan measurements and then calculating armspan can overcome this. For ease of measurements, arm length and tibial length are available. The tibial length data also reduced the flag data for the disabled population the most in the Indian data set. The final selection of measurements may be chosen based on the study population and confidence of field workers.

Table 4.1. Measurements to correlate with height in children.

Study	Sample	Measurement	R Value	Comment
Tompsett <i>et al</i> (1999)	Nigerian population, non-disabled, 2-10y. Field setting.	<ul style="list-style-type: none"> • Demi- span • Halfspan 	<ul style="list-style-type: none"> • R²= 0.87 • R²= 0.89 (P<0.001) n=199	Field workers found demi-span a difficult measurement to obtain accurately.
Socrates <i>et al</i> (2000)	Philippine population, non-disabled, 2-10y Field setting.	Armspan	R ² = 0.985 (P<0.001) n=64	Halfspan was actually measured and then multiplied by 2 for the armspan value.
Yousafzai <i>et al</i> (2001): Present Study	Indian population living in Dharavi, non-disabled, <7y. Field setting.	<ul style="list-style-type: none"> • Tibial length • Arm length • Armspan 	<ul style="list-style-type: none"> • R²= 0.721 • R²= 0.813 • R²= 0.932 (P<0.001) n=162	Halfspan was also calculated by dividing armspan by 2.

In the present study, the three derived heights (from equations) were used to calculate HAZ and WHZ scores for the disabled population, which would be the future application for such measurements. A more accurate description of HAZ and WHZ among the disabled population was then possible.

The range of options proved essential when dealing with children with physical impairments. Despite armspan having the strongest association with height, it is not always possible to measure in children with spasticity in the arms. It may be possible, with further investigation, to recommend universal equations for this age group in the future.

Body composition area has also proven to be complicated. Skinfolds were found to be sensitive measurements compared with MUAC for children with motor impairments

that cause increase upper body muscle tone. However, the skinfolds thickness cannot easily be extrapolated to percent body fat in malnourished populations because fat may be stored around the internal organs in preference to subcutaneous storage. Body fat equations have also been found unsuitable for cerebral palsy children (van den Berg-Emons *et al*, 1998). Therefore, these data require careful interpretation.

Weight measurements were less problematic than height. Three children with disabilities with non-ambulatory status were too heavy to lift and weight could not be taken. By observation, the children were obese and needed nutritional care. However, no means available to obtain an accurate weight.

All subjects were compared with NCHS references. Specific growth charts have been developed for DMD (Willig *et al*, 1993), Down syndrome (Cronk *et al*, 1988) and cerebral palsy (clinically severe) (Krick *et al*, 1996). These conditions are associated with poor growth, but nutrition still plays an important role in optimising potential growth and preventing malnutrition and other secondary problems. Finally, the use of such references would not permit a consistent approach in the study.

Another limitation of the present study was the difficulties in making comparisons with previous studies because of the variable disability classification methods. For example, Suzuki *et al* (1991) provides no clear description for the inclusion criteria for subjects classified as mentally retarded. Classification of disability has proven to be a large subject of research only briefly described in the literature review. The medical classification is not feasible for many field studies in the community. The impairment classifications (see Box 1.2, Chapter I, Literature Review, pp23) are useful and future studies must provide a clear description of methods used to classify subjects.

IV. Conclusions

- Attention toward the nutritional status of all subjects in the Dharavi study is needed. Prevalence of moderate-severe malnutrition by WAZ, (the expected most reliable anthropometric indicator of nutritional status) shows more than 40% of malnutrition for all groups. The dietary survey indicated only 5.2% had ever received some form of nutritional supplementation.
- Children with disabilities were identified as having a significantly poorer ($P<0.05$) means of nutritional status than controls by WAZ, HAZ, (and WHZ when derived height data was applied), TSF and haemoglobin. Micronutrient data from ferritin and vitamin D showed lowest means for disabled subjects. Vitamin D was significantly lower ($P<0.05$) for the neurological impairment group. Previous clinical studies regarding bone metabolism have recommended vitamin D and calcium supplementation for cerebral palsy patients (Baar *et al*, 1997), which may be important for the present subjects also. However, a larger sample size is required before further conclusions can be drawn. Subjects with neurological, motor and learning impairments appeared to be more vulnerable when case-control analysis was conducted by impairment group. However, the sensory impairment group also had lower means of nutritional status indicators compared to controls and it may be a sample size factor limiting observations of significant differences.
- Feeding difficulties was identified as a risk factor for vulnerability to inadequate nutritional status among subjects with disability. Carer responses about feeding difficulties were be useful in identifying the degrees of feeding problems and were associated closely with nutritional status. This can be useful for future work. Identifying children for malnutrition risk by the functional/activity limitation in feeding rather than impairment group/medical diagnosis would perhaps be useful in the future. This would be particularly valuable because there are a range of impairment groups and severity is variable, not all children in such a classified group would be at risk of malnutrition. Also, CHW in poor communities could be

trained to identify children through the functional limits in feeding using basic questions for carers such as those used in the baseline survey.

- Alternative measurements correlating to height resolved a major study limitation in assessing nutritional status by anthropometry.
- Focus group discussions with carers identified a lack of knowledge about disability and a lack of awareness about disabilities services. Carers needed more information on feeding management and basic nutrition. One means of informing carers was through workshops.

Future Work

- Further Analysis

An improved understanding of the interaction of factors affecting nutritional status of children with disabilities may be possible using more complex analytical methods, e.g. logistic regression, for future analysis.

- Much more work is required about the nature of nutritional problems for children with disabilities living in the community in developing countries; particularly about groups other than cerebral palsy, and for micronutrient data as well as anthropometry. Nor do we have sufficient information and means of investigating the nutritional status of children with disabilities in relation to other areas of child development. The Portage approach as part of this study design was not feasible. More information is needed for older children and adults with disabilities where factors other than feeding difficulties may play a role in contributing to nutritional status. There is little consensus about these groups in the literature.
- There is a need for intervention approaches. It is still not known whether workshops are effective in changing feeding management practice and thus, have an impact upon nutritional status. Other means of intervention (whether delivered through disability services or mainstream primary health care/Nutrition programmes) have not been explored at all.

- Although, it may be assumed the extent of malnutrition may be less for children with disabilities in higher income communities, we still know very little about the nutritional status of those with milder disabilities not frequently seen in clinical settings. This has been commented on by other researchers (e.g. Corwin *et al*, 1996). It is not acceptable to accept poor growth and nutritional inadequacies among people with disabilities by suggesting it is entirely because of the health condition.
- There are still many unresolved issues that need further investigations, e.g. the interactions of the primary disease process in some disabilities such as DMD, a better understanding of intestinal function for children who experience gastro-intestinal reflux, greater evaluations of bone mineralisation process.
- The priority for all children is to ensure that they are adequately nourished. Nutrition research can also focus on optimising the child's development through nutritional therapy; (e.g. Ani *et al*, 2000; in progress: trials to evaluate the benefits of anti-oxidants for Downs syndrome children).

The renewed interest in nutrition and disability needs to be maintained in order to develop beneficial public health guidelines both in developing and developed countries.

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World Wide Web Reference Material

APD: http://www.indiainternet.com/apd/	June 1999
Census of India 1991: http://www.censusindia.net/	September 2000
Dharavi Picture: http://www.robertappleby.com/	January 2001
Maps of India: http://www.Mapsofindia.com/	January 2001
Mumbai Pages: http://theory.tifr.res.in/bombay/history/slums.html	September 2000
Samuha: http://www.samuha.org/default.html	June 1999
SSI (Eastern India): http://www.southasia.com/spacsoc/	June 1999

Appendices

Map of India



Mumbai is in Maharashtra State.

Maharashtra covers an area of 307 713 sq. km.

Greater Mumbai district (including Mumbai city) is India's most populated with a population of 78 937 187.

Map of Mumbai



Population of Mumbai Metropolitan region: 12.5million. Dharavi is located 10Km North from the city centre. Dharavi area: 4.5sq. Km.

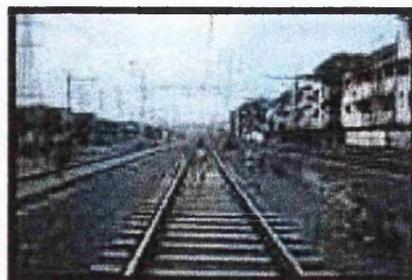
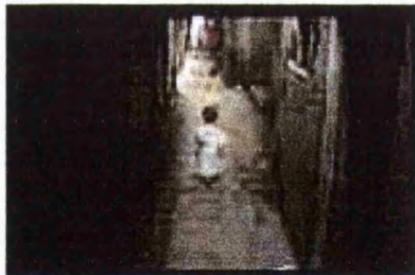
Images of Dharavi

The map does not enable a clear picture of Dharavi. It is a contrasting area with both new emerging make shift areas (*kuccha*) and older solid areas (*pucca*). The following images are taken by photographer Robert Appleby: (<http://www.robertappleby.com/Dh/Dhcontact.htm>).

Make shift or kuccha areas (relatively newer parts of Dharavi and less serviced, eg. Ragiv Gandhi Nagar)



More established areas, (e.g. Ambedkar Nagar). High rise buildings can also be seen in such areas.



Personal Photographs from Dharavi

1. One of the field team (Vayjayshree Jadhu) during data collection.
2. A participating family.
3. Questionnaire in progress.
4. Local girls.





Appendix 2: Baseline Survey Questionnaire

NUTRITION AND DISABILITY PROJECT: QUESTIONNAIRE

PROJECT IDENTITY NUMBER OF CHILD: _____

NAME OF FIELDWORKER: _____

RELATIONSHIP OF INTERVIEWEE TO CHILD: _____

DATE OF INTERVIEW: _____

(The interviewer should introduce themselves, who they work with, and why they are doing the questionnaire)

THE TEN QUESTIONS SCREEN FOR DISABILITY

(COPYWRITE: THE RAPID EPIDEMIOLOGY ASSESSMENT OF CHILDHOOD DISABILITY ASSESSMENT PROJECT, 1988)

1. COMPARED WITH OTHER CHILDREN, DID THE CHILD HAVE ANY SERIOUS DELAYS IN SITTING, STANDING OR WALKING? YES * NO

If NO, skip to Question 2

If YES, probe: "Did the child walk by the age of 2 years?" YES NO

2. COMPARED WITH OTHER CHILDREN DOES THE CHILD HAVE ANY DIFFICULTY SEEING, EITHER IN THE DAY TIME OR AT NIGHT? YES * NO

If NO, skip to Question 3

If YES, probe: "Is the difficulty only at night?" YES NO

"Can he/ she see that?" (point to a small object in the home) YES NO

"Does he/ she have some either eye problem?" YES NO

(If YES to this probe, write down what the mother says:)

3. DOES THE CHILD APPEAR TO HAVE DIFFICULTY HEARING? YES * NO

If NO, skip to Question 4

If YES, probe: "Can the child hear at all?" YES NO

"Does he/ she have some other problems with his/ her ears?" YES NO

(If YES to this probe, write down what the mother says:)

4. WHEN YOU TELL THE CHILD TO DO SOMETHING DOES HE/ SHE SEEM TO UNDERSTAND WHAT YOU ARE SAYING? YES NO *

If YES, skip to Question 5

If NO, probe: "If you ask him/ her to bring you a cup, (but you don't point), is he/ she able to do it?"

YES NO

5. DOES THE CHILD HAVE DIFFICULTY IN WALKING OR MOVING HIS/ HER ARMS OR DOES HE/ SHE HAVE WEAKNESS AND/ OR STIFFNESS IN THE ARMS OR LEGS?

YES * NO

If NO, skip to Question 6

If YES, ask all of these questions: "Does he/ she need help in walking?" YES NO

"Does he/ she use his/ her hands to pick things up?" YES NO

"Does he/ she have stiffness?" YES NO

"Does he/ she have weakness?" YES NO

6. DOES THE CHILD SOMETIMES HAVE FITS, BECOME RIGID, OR LOSE CONCIIOUSNESS?

YES * NO

If NO, skip to Question 7

If YES, probe: "Has he/ she had a fit in the last year?" YES NO

"Do the fits interfere with his/ her usual activities (like doing chores or going to school, if old enough)?" YES NO

"Do they occur only with fever?" YES NO

7. DOES THE CHILD LEARN TO DO THINGS LIKE OTHER CHILDREN HIS/ HER AGE?

YES NO *

If YES, skip to Question 8

If NO, probe: "Can you tell me about something he/ she seemed to have difficulty learning?"

YES NO

"Does the informant give an example?" YES NO

If ^{YES} ~~NO~~, write down the example.

8. DOES THE CHILD SPEAK AT ALL (CAN HE/ SHE MAKE HERSELF UNDERSTOOD IN WORDS; CAN HE/ SHE SAY ANY RECOGNISABLE WORDS)? YES NO *

9. FOR 3 -9 YEAR OLD CHILDREN ASK: 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)? YES * NO

If the parent responds YES check YES. If the parent responds YES or NO because the child cannot speak at all, leave question 9 blank and skip to question 10.

If NO, skip to Question 10

If YES, probe: "Does he/ she stammer or stutter?" YES NO

"Does he/ she have some other problem with his/ her speech?" YES NO

(If YES to this probe, write down what the parent says:)

9. FOR 2 YEAR OLD CHILD ASK: CAN HE/ SHE NAME AT LEAST ONE OBJECT (FOR EXAMPLE, AN ANIMAL, A TOY, A CUP, A SPOON)? YES NO *

If YES, skip to Question 10

If NO, probe: "Does he/ she use his/ her own words for things, like bow-wow for dog?" YES NO

10. COMPARED WITH OTHER CHILDREN OF HIS/ HER AGE, DOES THE CHILD APPEAR IN ANY WAY MENTALLY BACKWARDS, DULL OR SLOW? YES * NO

If YES, probe: "Would you say that he/ she is much behind other children his/ her age, that he/ she acts like a much younger child?" YES NO

DOES THE CHILD HAVE ANY SERIOUS HEALTH PROBLEMS NOT YET MENTIONED?

YES NO

IS THERE A DISABILITY: _____

(IF YES, STATE THE DISABILITY)

Interviewer: The questionnaire result is positive if the response to any one or more of the ten questions has an asterisk (*) next to it. If no response has an asterisk (*) next to it, then the result is positive.

SHOULD THE CHILD BE REFERRED FOR PROFESSIONAL EVALUATION?

1. No, because the questionnaire result is negative.
 2. Yes, because, although the questionnaire result is negative, there is a query.
 3. Yes, because the questionnaire result is positive.
-

A: QUESTIONS FOR ALL CHILDREN

Name of Child	
Sex	
Disabled (D) / Sibling (S) / Neighbour (N)	
Age (y)	
Address	

INFORMATION ON FATHER:

Father's Name		
Age of Father (y)		
Education	Not at all	Standard Completed
Can Father Read	Yes	No
Can Father Write	Yes	No
Occupation of Father		

INFORMATION ON MOTHER:

Mother's Name		
Age of Mother (y)		
Education	Not at all	Standard Completed
Can Mother Read	Yes	No
Can Mother Write	Yes	No
Does Mother Work Outside of the House	Yes	No

INFORMATION ON FAMILY:

Religion	
Length of Time Living in Dharavi	
Place of Origin (if known by family)	
Number of Children Born to Mother	
Birth Order of Subject	
Who is the Main Caregiver for the Child	
If the mother works: Who is the main Caregiver for the child while she is away from the house	

INFORMATION ON HOUSING:

Type of House	Pucca	Mixed	Kuccha
Flooring	Concrete	Tiles	Other
Walls	Brick/Concrete	Corrugated	Makeshift

Number of People in House	Adults (>15)	Children	
Type of Family	Nuclear	Extended	Joint

DOES THE HOUSE HAVE:

	YES	NO
Beds		
Chairs		
Light		
Fan		
T.V.		
Video RADIO		
Grains/ Food Stores		

FOOD PREPARATION

Is Food Prepared Using	Gas	Coal	Wood	Kerosene Stove
Types of Pots Owned	Aluminium	Steel	Iron	

B: QUESTIONS FOR ALL CHILDREN

FOOD FREQUENCY TABLE:

Food Type	Frequency					Frequency Per Day
	D	W	M	R	N	
Pulses: (Beans, Dahls)						
Breads/ Grains:						
Chappatis						
Bread						
Rice						
Meat: (Chicken, mutton, pork, beef)						
Fish: (Any fish)						
Dairy Product:						
Milk						
Eggs						
Other (buttermilk, cheese, yoghurt)						
Fruits: (Any fruit)						
Vegetables: (Any vegetables)						
Liquids:						
Tea						
Rice Water						
Vegetable Water						
Coconut Juice						
Sweet Water						
Fruit Juice						

NB: (D= Day, W= Week, M= Month, R= Rarely or O= Occasionally, N= Never)

NB: (Please note any particular comments made by interviewee on food intake, e.g. vegetarians, religious, any other habits)

Is Food Mainly Prepared Using	Vegetable Oil	Butter	Ghee	Other
-------------------------------	---------------	--------	------	-------

Is there any food you feel is bad for your child, (e.g. He can't eat it or it makes him sick)	Yes	No
---	-----	----

If YES then what is it?	
-------------------------	--

Do you give your child something special to make him/ her sleep like a tablet:	Often
	Sometimes
	A Little
	Never

Has your child received nutritional supplements before?	Yes	No
---	-----	----

If YES, then when, where from and what was the supplement, (e.g. From school, etc)	
--	--

C: QUESTIONS FOR DISABLED CHILD ONLY

DOES YOUR CHILD:

Have Difficulty chewing or swallowing	A Lot	Some	Never
Need help feeding him/ herself	A Lot	Some	Never
Eat the same food as the rest of the family	Little	Some	All
Eat specially prepared food (i.e. liquidified)	Liquid Only	Mashed/ Cut	No
Vomits or regurgitates food	A Lot	Some	Never
Eats at the same time as the other children	Never	Sometimes	Usually
Takes longer to eat than the other children	Usually	Sometimes	No
Go outside when the other children do	Never	Some	Usually

If the child needs feeding by you. is he/ she fed:	Sitting Up
	Lying Down
	In Your Lap
	Other

ADDITIONAL INFORMATION:

How is your child able to walk:	Normally
	With Difficulty
	With Stick/ Crutch
	With Human Assistance
	Not At All

How is your child able to move his/ her arms:	Left Arm	Right Arm
Normally		
With Difficulty		
Not At All Able to Move		

(THANK YOU VERY MUCH FOR YOUR HELP)

Appendix 3: Focus Group Analysis

- An example of a qualitative mind map for focus group number 2.
- An example of a qualitative mind map for a MAJOR emerging theme that summarises information from all focus groups.
- An example of the final coded transcript (shown for focus group 2). Final codes are in blue ink.
- Descriptive summary of each theme.
- Tabulated summaries of the focus groups.
- Transcript translation sample done by objective researcher.

-at least not in the neighbourhood.

1 TYPES OF DISABILITY KNOWN → walking (pp1)
(wrt: their dis children) → Visually (pp2)
→ Mentally (pp2)
→ Speech (pp2)
povo (pp3)

2 BELIEFS WRT DISABILITY → Mother in law would not give permission for immunisation in village against polio. (pp3)

3 PARENTAL FEELINGS → Frustration / helplessness. (pp2)

Frustration (pp3)
a lot of hard work (x busy)
Frustration when child doesn't seem to follow normal pattern for age (leg: ability to help in the house) (pp7)
leg: hasn't learnt to speak
Frustration when child appears not to respond to treatment. (pp2)
Treatments - long term plan is too long for treatment when child appears not to respond to treatment. (pp2)

Search for treatment important, want best for child. Come to Dharavi (city) from village specifically for this reason (pp2) (pp3)
Pain (pp8): "Pain would stop if she died I got better. Must not give up hope."
physical impairment barrier to marriage (pp7)
concern w/ dependency / aftercare: child may be burden on ageing parents + siblings (pp3)
Day-to-day care: food / clothes more important than future marriage for children. Priority care / treatment. The rest is upto GOD (pp7)

4 FUTURE → All want best for children

Feel by family / friends all children treated the same (pp4)
Children mix. Some it is harder. Again dependent on disability type / severity. (pp4)

Anger at system - discriminated against poverty (pp5) (pp6)

6 NEEDS → Basic services listed as wake community need. Priority before specialised needs for disabled children: eg: Light (electricity), Food, Water.
Do not feel dis / non dis same access to services.
They go on to talk of practical barriers (eg school thinks child gets sick more easily... can't cope & parents worried how child treated. (pp4)

Accept education important service but more importantly for dis child is basic survival skills. (pp4)
When you consider needs education valued but costly. Basic needs must first be met (eg: dah, rice). Area needs H2O. Cleaning required - kids get malaria. Without the basic necessities in place too many practical difficulties. Makes life busy. eg: getting birds ready - usually late for school. no water supply - takes dis. child even longer. Then teacher gets angry. (pp5)

Anger at hospitals. (pp5)
- not treated well
- things not properly explained

7 FOOD / NUTRITION → Good food - meat / eggs = expensive. (pp6)
Discuss feeding difficulties in children. Feed must eat more for strength. Key point: dis child seems less interested in food (than sibs).
No special food prepared for dis child. Gets same as rest of family. Diet is monotonous. No choice (pp7)
Interest in workshops. Fit into practical time of day (H2O > 10:30am)

① DISCRIMINATION (DISCRIM)

→ Shame

Focus grp 1: shame of disability was experienced by some parents. Some parents may hide the disability. At times disabled children are hidden away. Such incidents were come across when SS1/AMU surveying their area: BARE

→ Focus grp 4 & 5 & 3
Expressed sympathy

Focus grp 1, 2, 3, 4, 5:
On the whole did not feel a great deal of discrimination in the community.

Focus grp 3: parents of disabled children said sometimes they preferred to keep the child indoors - from fear that somebody may say something hurtful. Although in practice this very rarely happened.

Focus grp 1: Teachers felt: those who earn a bit receive preferential treatment in the family. Boys receive preferential treatment in our country compared to girls. Disabled girl probably receives very low attention from parents. The concept is related to how "PRODUCTIVE" a family member is.

Acceptance

Focus grp 1: Children that were disabled were accepted in the community. Often the inclusion of a disabled child in play/activity was dependent upon the type/severity of the disability. eg: Easier for children with polio or hearing impaired that can communicate with gestures.

Focus grp 2 } Children do mix. Usually it is dependent upon the type/severity of the disability.
Focus grp 3 }
Focus grp 4 & 5 }

→ Ignorance

Focus grp 3: - child (speech) excluded from school. Teacher said he couldn't learn anything - stupid. This also reflects lack of means/training in organisations.
- case: child beaten by ignorant adult.

Focus grp 3: In one case the mother said she preferred child to be indoors with her in case of trouble outside when the child would not be able to tell her because of his speech impairment (or get help).

Focus grp 3: In another case the child was kept indoors because he became anxious and frightened outdoors (eg: if he saw a fight he would think he would be hurt).

Focus grp 2: Feel the children are ALL treated the same by family and friends.
Went best for ALL children. (focus grp 3) (focus grp 5)

Support

Focus grp 1: created SUPPORT was a NEED for all carers of disabled children. Neighbours & relatives are helpful in taking care of a child. examples of helpfulness shown eg: letting a disabled person ahead in the queue.

Focus grp 5:

Focus grp 3: Felt received no support from neighbours. Each to his own attitude. This was because people had no means or time to help; only show sympathy (focus grp 5)

busy

Focus grp 1: People in Dharavi had no time to chat about concerns; too much work. Carers of disabled children were not isolated - they too are busy. Considering practical issues for survival. They don't sometimes have the time to care thoroughly to the special needs of disabled child. eg: feeding (also seen in focus grp 3 and 5).

Anger
Focus grp 2, 4, 5: Most discrimination: poverty barrier not disability.

FOCUS GROUP 2

DATE: 03/03/99
PARTICIPANTS: Parents of disabled children living in Ambedkar Nagar
GROUP LEADER: Sunita Pagedar (SP)
OBSERVERS: Aisha Yousafzai and an AWW/SSI
LOCATION: Church, Ambedkar Nagar
LANGUAGE: Hindi
TIME/DURATION: 11am, 35minutes

SP: We are here to discuss nutrition and disability. We wish to understand your views on these subjects. You all have disabled children. Tell me about your children. Do you have a disabled child?

⇒ No, she will not understand. Ask him? (*points to a man*)

SP: Him?

⇒ It is her brother in law. Speak to him.

SP: Is this your child?

⇒ It is his brother's child.

SP: His brother's child. What happened to the child? (*pause*)please speak freely.

⇒ I don't really know anything.

SP: OK...does the child not speak or not walk? What is the problem?... Don't be embarrassed to speak. The ladies will all speak openly also!!!

⇒ (*another lady speaks*).... the child speaks, he walks.

SP: Yes, yes. Let him speak.

⇒ (*another lady speaks*)...they have just arrived from their native place. They will not speak easily here.

⇒ (*the man speaks*)....he doesn't walk properly or evenly.

SP: He doesn't walk?

(lots of ladies say "yes" in the background)

AWW/SSI: This teacher (*Sunita*) will ask questions and you just give an answer.

(heard in background speaking to the man)

⇒ (man replies) He doesn't walk evenly.

⇒ This is her son. Look at him walk.

SP: I see.

⇒ (*mother speaks*)...his feet are not even. He was born in our native place. As he grew older he never started to walk. Then we came here (*Dharavi*) to look for treatment. He was little then. Now he is older, he can walk a little.

SP: He can walk now?

⇒ Yes. He will walk for a short time, but then he will tire out and he falls down a lot because he has no strength.

SP: No strength?

⇒ It has been like this for a year.

SP: OK.

⇒ It is just that his feet aren't balanced....see....

SP: And what about your child?

⇒ This lady's son, since two years of age, can neither see properly nor can he understand things. He needs to be completely looked after.

SP: OK

(interruption due to a mother coming in a little late because she had to finish her housework).

SP: What about your child?

⇒ My daughter is thirteen years old. She became like this in childhood. She was fine, then at nine years of age she became like this. Since then we have been going to hospitals and trying to find treatments. But she does not get any better or worse. It is

really hard. She will be a burden to us all- mother, father, brothers. We expect our children to help us by this age, but she can do nothing.

SP: She was fine previously?

⇒ At first she was fine. She was fine when she was born. Then she stopped speaking clearly... and now what you see in front of you?

SP: Does she understand when you speak to her?

⇒ Yes, she understands.

SP: What about your child?

⇒ Around six or seven months he got polio.....and now his leg is bad.

SP: Did you ever give anything for polio....those drops?

⇒ No. My mother-in-law would not permit such things. We were in our native place. Anyway, he got polio. He had a fever. And well, then he couldn't walk. We did not know anything about it or about what we could do to help our child. My husband was here (*Dharavi*) and then we came to join him. When my son was two years old, he had an operation on his foot. Now he is five years old. He can walk a little with help- he holds on to things.

SP: OK. So what differences do you see in raising your disabled children from your other children?

DIS ⇒ There are more worries

DIS ⇒ It is a lot of hard work

⇒ I am worried. My daughter doesn't speak.

SP: Not at all?

No. She should speak, but she only says "mama" or "papa". She doesn't understand a thing. It is too worrying.

SP: Do you feel people in your neighbourhood treat you differently because you have a disabled child?

DISCRIM
DIS ⇒ No, nothing like that happens.

SP: Are people helpful to you, for example relatives.....Do the children all play together?

DISCRIM ⇒ For all of us, all of our children are the same. They are all important.

DIS All the children play together. In the family, they are treated the same by aunts, uncles and grandparents.

SP: And you all feel the same?

⇒ Yes (*group reply*)

⇒ It is harder for my child because she cannot speak, but she does play.

SP: In this area what services do you feel are lacking? What would you need for your disabled children? For example; schools, treatment, nutrition, somebody to talk to.....if you had a problem where would you go?

DIS ⇒ Light.

DIS ⇒ Food.

DIS ⇒ We need water.

SP: Do you think your disabled children have the same access to services as the non-disabled children?

SERV ⇒ Not at all.

DISCRIM DIS ⇒ To send my child to school is hard. They think he will get more sick and we all worry how the others will treat him.

DIS ⇒ It would be good to have education. However, it is enough that these children should no a little to survive like their own name..... Of course we would love to give all our

children the best education, but how many things must we think about. We don't earn enough money. For us, to fill our stomachs everyday with dahl, rice and bread is enough.

NEEDS

⇒ We don't even have a proper water supply.

NEEDS

⇒ Nobody has cleaned our area for over six months. Our children get sick more often. They get malaria again and again. They are sick for fifteen days at a time. People come here and say we will do this and we will do that, but nothing is ever done.

NEEDS

⇒ We just have to survive. Someone does a cleaning job in a house, someone does this and that and we fill our stomachs and run our homes. That is all we have. What more can we tell you.

NEEDS

(for)

⇒ We send some of our children to school. But it is so much trouble. Like the anganwadis start at ten in the morning. Teachers complain our children are always late, but we do not even get water until eleven - eleven-thirty. It takes time to get this one ready (points to her disabled child)

SP: Do your children go to school?

⇒ Yes

SP: Where?

⇒ Sion

SP: ..and you?

⇒ They go to a balwadi close by.

SP: Despite all this trouble you all still try to send your children to school?

⇒ Yes, if the school takes the child, of course we do.

⇒ Not all the schools accept them (*disabled children*)...my daughter is too difficult.

DIS

DS

SERV

⇒ Yes..yes (*group response*)

⇒ The hospitals here are the same.

⇒ Yes... Sion hospital, well nothing really works there. For so many treatments we take the children. They just fob you off with excuses. My daughter doesn't sleep- its hard, they don't care.

⇒ Nothing helpful in Sion (*hospital*)

⇒ You go upstairs (*to the pharmacy*) for the medicine.....nobody asks about you again.

⇒ Nobody explains anything.

⇒ It all costs money.

(Fair)
DIS ⇒ Because we are poor, they treat us like this. They shouldn't do that. We have brought these children in to this world and must do our best to look after them.

⇒ Everything is a big obstacle for us.

SP: I see. Lets chat about nutrition for a while. What do you think of as good food for you?

FOOD
FOOD ⇒ Dahl, rice, meats, eggs.

SP: Do any of your children have eating or drinking problems?

FOOD
FOOD ⇒ He will try to eat on his own.

FOOD
FOOD ⇒ He will eat as much as he can, but it is hard for my child.

FOOD
FOOD ⇒ My child cannot eat on his own.

SP: And what about your child?

FOOD
FOOD ⇒ She (*sibling*) will eat everything; mutton, fish. We cook everything at least once in two weeks. But this one (*disabled child*)- he doesn't eat.

FOOD
FOOD ⇒ My child has no strength.

SP: Does your child eat?

⇒ No. She doesn't eat mutton or fish. Just dahl, rice. All vegetables, especially potatoes.

SP: Are you able to afford fish?

⇒ Yes, but she doesn't like it. That's all. She is frightened of the bones.

SP: Even if you take the bones out?

⇒ Yes, she is still frightened.

SP: Do you think it is more important for disabled children to eat well?

⇒ I want my child to be stronger.

OOD ⇒ Yes, I worry because my child doesn't like food but needs to eat more.

FOOD ⇒ But what else can we feed them. We can only give what the rest of the family is given to eat.....dahl, rice.

SP: If we ran workshops on nutrition and how to help your disabled child to eat better, would you all come? We would not talk about expensive foods or anything like that.

⇒ Yes (*group response*)

FOOD ⇒ It would be good, but you must hold them in the afternoon. There is no water problem then. But before our husbands come home or we have to collect our children from school. Two o'clock is good.

SP: Yes. We are sorry for today.

⇒ Don't worry. Just tell us the day before the workshop and we will always come.

SP: Have you thought about the future for your disabled children? (pause)... jobs, marriage.....

RE
UT { ⇒ If he is going to stay like this, with the walking problem, how can we think about marriage.

⇒ We don't think that far in to the future. First we think that our child should get better.

⇒ The future is worrying. Who will care for the child. At the moment we just think about feeding and clothing our children. The rest is up to God.

⇒ Right now we have enough everyday problems. I can't think of him getting a job or surviving on his own.

⇒ Right now we have enough tension. Look at her. She grows older but more dependent. She cannot help me with the housework. I have to look after her. If there is a cure there

would be no tension, if she died there would be no tension. But it will be like this forever. Her father says accept the situation, there is no cure. But the pain of a mother is too great, how can I stop trying. Mothers cannot give up.

DIS
DIS

(group agreement)

⇒ Which mother doesn't want the best for her child. My child can't eat. First I must feed her, cloth her.....

FUTURE
FUT
IS
DIS

⇒ First, I want my daughter to start talking. Then I will think of her future. All I want is for her to speak.

SP: It sounds very difficult. Thank you for sharing your views with us.

⇒ Thank you for letting us talk. It was good for us to.

SP: We learnt a lot. Sorry for the time we set, sometimes we do not think of realities when we are in the office!!!!

Key

Final Codes:- DIS - Acceptance for Disability at Family + Community Level

FOOD - Food and Nutrition

SERV. - Services and Needs

FUT - Future

DESCRIPTIVE SUMMARY OF EACH THEME

1. ACCEPTANCE OF DISABILITY- VIEWS ABOUT DISABILITY

- A lot of frustration and worry was felt by carers. Some were concerned that their disabled children were not capable of anything. They worried more because they did not know what to expect- they did not see the normal pattern of development, (unable to help in the home, run errands, laugh, play the same). Other times the frustration came from a lack of knowledge. Parents did wish to know more. They felt things had not been properly explained to them. Parents were also tired because it was such a lot of hard work, particularly if they worked outside of the home, to raise a disabled child. Financial concerns for families with disabled children were mentioned briefly in one discussion as it was felt lots of money was needed for medicines, etc. (*see sections 4, 5 and 6*)
- Treatment, often private, was a major pre-occupation. Often a reason to stay in the city rather than village. A few had never seen a doctor or had any explanation given (or understood the explanation). (*see section 5*)
- A range of disabilities were described. People only observed disability if they knew a friend or relative that was disabled. Children who could not speak or who drooled are often referred to as “mental”.

2. ACCEPTANCE OF DISABILITY- SUPERSTITIONS AND BELIEFS

- Field workers said some parents believed disability was due to a curse or past sin. Only one mother kept referring to her “bad fate”. (*see section 6*)
- The faith in the “Goddess Devi” came up as a common belief in treating sick children which led to stopping medicines and therapy for one disabled child which slowed the child’s progress. During a time of illness, all faith is put in prayer to the Goddess. The

medication is stopped for the first few days, as the child will be in too much pain. The fever is allowed to run its course and all the impurities can come out. Simple foods are eaten only. *(see sections 1, 4 and 5)*

3. ACCEPTANCE OF DISABILITY- IMMUNISATION

- One child, disabled due to polio, was born in the village. His paternal grandmother had refused to allow for immunisation. This was heard of a few times when people were questioned casually. Some were unaware of immunisation until too late, (usually in the villages). *(see section 1 and 5)*

4. ACCEPTANCE OF DISABILITY- DISCRIMINATION

- It was not felt by anyone in the focus groups that there was a great deal of discrimination in the community against disabled children. In many cases they felt that any discrimination was not due to the disability but was by the authority due to their poverty, e.g. people were not aware of services provided by the council in Dharavi to help care for disabled children. *(see section 6)*
- The field workers felt that sometimes preferential treatment existed in the home. Family members who could earn a little were given preferential treatment- they were more “productive”. A general comment made was, “ In our country girls are treated worse than boys anyway. So a disabled girl will receive very little attention at home.” People felt that all of the children (disabled and non-disabled) were treated the same by family and friends. Some parents did add that often they were too busy to give all their children the attention they needed, (particularly disabled children who need more time and patience). The theme of “time” is repeated through out discussions in relation to feeding and general care. *(see section 5)*
- People said family and friends were supportive and helped out when they could. At the same time there was a limit to the support that could be given as everyone in Dharavi

is poor, has problems and are busy. People could do little more than be sympathetic. Some examples of helpfulness were illustrated; e.g. letting a disabled adult ahead in a queue.

- Cases of “shame” due to having a disabled child were rare. The field workers had only come across a few cases where children were “hidden” in the home and the presence of a disabled child was not disclosed. Parents of disabled children said they sometimes preferred to keep their children indoors form fear that someone may say something hurtful. Although they also said this was not commonly experienced. Two mother’s explained why they preferred to keep their disabled children indoors:
 1. The child becomes anxious outdoors. If he sees a fight between adults, he also thinks he will be beaten.
 2. The child has speech and hearing impairments. The mother feared if something were to happen to him he would not be able to tell her clearly or get help for himself.

In one case, a disabled boy (hearing and speech difficulties) had been beaten by an adult after a squabble between children turned nasty. In each case the mothers were being very protective of their children.

- The disabled children did play with the other children in the community. Often, the inclusion of the disabled child in any play or activity was dependent upon the type and severity of disability. For example, it was felt that it was easier for a child disabled due to polio to mix with other children, or a hearing impaired child who could still communicate by gestures.
- Not many children (disabled or non-disabled) went to school form the focus group sample. One mother had tried to send her child to school. He was speech impaired. The teacher refused to teach him saying the child was stupid. This partly reflects an ignorant attitude, and a the lack of training or means for the child to go to school and join in. (*see section 6*)

5. FOOD AND NUTRITION

- The everyday diet is monotonous. Usual foods are dahl, rice and bread. Vegetables are eaten, (not usually in great quantity or variety). Rice and dahl is also easy to prepare and doesn't take long and can be re-heated which are big advantages. Children are sometimes given "chagri" for energy 2-3 times a week. The every day foods are thought of as good for health along with emphasis put on "luxury" items like meat, fish and eggs, which are more rarely eaten.
- Poverty is the limiting factor in providing enough food. Most of the money earned is spent on food. Often there is not enough for all the meals and sometimes a child or a woman may go without or with less, (perhaps related to "productivity" (*see section 4*)). Even the basic foods are expensive, (e.g. may have pickle instead of vegetable or you may mix the vegetable with dahl to fill the stomach). A 1kg bag of rice or flour can cost Rs.10-12 and a bunch of spinach up to Rs 4.5. Items like yoghurt are too expensive. In monsoon, daily labourers run out of work, but they either return to the village or rely on relatives or find other employment. It is too difficult to store food for the season for most people. Knowledge of nutrition is not useful if you cannot afford the right food. (*see section 4*)

e.g. One carer explained how the husband earns only Rs. 70 a day as a daily labourer. His line of work runs out during the monsoon. They live in an extended family and so become dependent on the other earners. It would be impossible with such pay to buy extra food and store anything for the rainy season.

- One child received supplements from a balwadi (play group). From the children who attended school no one had received supplements. Parents were disappointed that the supplements from Municipal schools was now withdrawn as this made up for shortcomings at home.

- Different dietary habits in the different regions of India are reflected in the communities of Dharavi.
- People said they often found they ate better in the village- but came to Dharavi for work or treatment, etc. (*see section 1*)
- Disabled children did not receive any special foods. They were given the same as the other children in the family. It was not felt that families with disabled children were under more pressure than others to provide enough food, (although as adults in the future it may be tougher). It was thought to be just as hard as if you had many children to provide for. Mothers were concerned by the eating habits of their disabled children. Many said the disabled children seemed less interested in food than the siblings. They wanted the disabled children to eat more in order to gain strength. In one case, a mother was so concerned she said she forced dahl or vegetable water down her child to ensure she ate something. Feeding difficulties were discussed. Some people were afraid the child may choke. The field workers felt that some disabled children were malnourished if they were dependent feeders and the family had to work. This was confirmed by parents who felt they had no choice but to work and felt they could not give the child the full attention required. (*see section 4*)
- Interest was shown in workshops. (*see section 6*)

6. SERVICES AND NEEDS

- Priority was on basic necessities: food, water, clothes, toilets, gutters, light/electricity, schools, toys, work, a clean area so the children would not get sick and safe roads, (a child in the group had recently been in a serious accident). Illegal supplies of water and electricity are common.

e.g. people were charged for illegal electricity supplies of Rs. 100 per electrical item owned even though in most cases you could only run one item at a time. Legal water

supplies in most areas ran between 6.30am and 10.30am, the people have to queue in long lines. Illegal suppliers charged Rs. 1-5 per bucket.

Education was stated as a need- but too many barriers for it to be a realistic option for many families in Dharavi. Schools were far away and money was needed for lunch, buses, shoes, bags, books, uniforms, etc. Some parents had heard of special schools for disabled children, however, these were usually too far away and it would be difficult to send one child to one school and the others else where. It was felt that for the disabled children daily living skills were more important.

Knowledge about disability was also stated as a need.

It was once mentioned that parental support and financial support, (for special aides) was also needed for carers of disabled children. *(see section 1)*

Much anger was put in the council systems (hospitals, politicians etc.). It was felt that everything was made an obstacle for poor people. There was also a lack of awareness of what was available in Dharavi. *(see section and 6)*

It was felt that no child got everything deserved, and disabled children even less. They felt that access to services was poor for disabled children and they were hardly thought of by planners and organisations.

FUTURE

It was difficult for the participants to discuss the future. They are more concerned with day to day living; for example ensuring they have enough basic necessities for the family like food and clothes. Some said that the children would have a better future with education. It was clear that education was deeply valued, but was not a priority when they had to first eat, etc. In one example, a non-disabled son had left school because he felt that even with an education he would not get a good job and he saw earning money now as more important. The immediate future was more important. *(see section 6)*

	FG 1	FG 2	FG 3	FG 4	FG 5	Total No. Groups
Participants:	Staff	disability carers	disability carers	non-disability carers	non-disability carers	-
Area:	Dharavi	Ambedkar	Ragiv Gandhi	Ambedkar	Ragiv Gandhi	-
need more awareness of services for disabled	✓	✓	✓			3
priority immediate future for all		✓	✓	✓	✓	4

Transcript Translation Sample

Taken from focus group 3.

1. Original transcript:

SP: What problems do your disabled children have? How did you find out about the problems.

⇒ There is nothing to find out really.....at first when she was born- I mean she was normal. Then after would she got sick, and well after that she could neither stand nor could she sit up, nor was she able to walk. She is one and a half now. By one and a half, normally a child is walking. But she could not do anything...nor could she talk.. Someone had come to the house to see her and said she had a problem. That is why when she came to tell us of this meeting to discuss these problems We are interested in getting information and thought we might find out about the child's problem.

SP: Have you taken her to the doctor?

⇒ Yes, we have.

SP: What do the doctors' say?

⇒ She has been treated for awhile at the Barbaa hospital, but so far it has made no improvement

2. Translated by objective researcher:

A - Can you tell me about your child's problem. How did you find out about it?

Mother - There is nothing to find out really. When she was born she was little normal. But after she got sick she could neither stand nor sit, not capable of walking. She is about 1.5 year old. At 1.5 year a child walks around the mother but she doesn't and can't even talk. Someone had come to our house to see her and said she was a

problem. We are interested in getting information and thought we might find out about the child's problem.

A - Did you take her to the doctor?

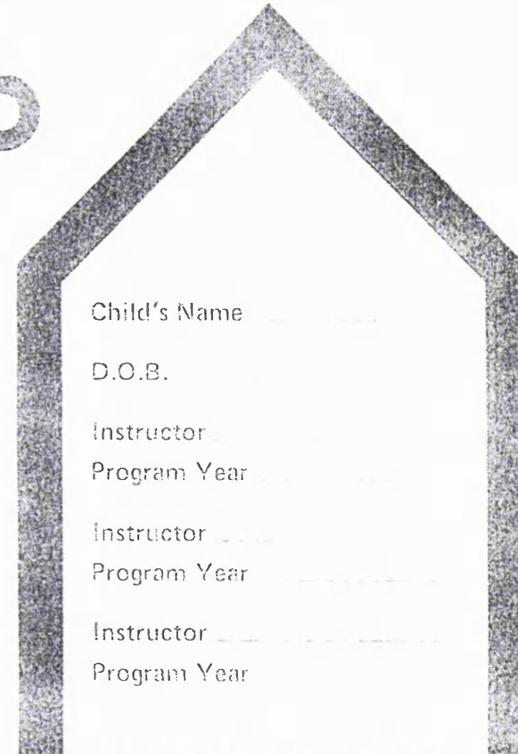
M - Yes we showed her

A - What do the doctor's say?

M - She has been treated for quite a while at the Bhabha hospital but there has been no improvement

Appendix 4: Portage Checklist

Portage Guide To Early Education



Child's Name _____
D.O.B. _____
Instructor _____
Program Year _____
Instructor _____
Program Year _____
Instructor _____
Program Year _____

S. Bluma, M. Shearer, A. Frohman, and J. Hillard

CHECKLIST

infant stimulation

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
Infant	1	General visual stimulation (Under six weeks)		/ /	
	2	General visual stimulation (six weeks and older)		/ /	
	3	General tactile stimulation (Under six weeks)		/ /	
	4	General tactile stimulation (six weeks and older)		/ /	
	5	General auditory stimulation (Under six weeks)		/ /	
	6	General auditory stimulation (six weeks and older)		/ /	
	7	Sucks		/ /	
	8	Moves head to side while lying on back		/ /	
	9	Opens mouth for bottle or breast when nipple touches mouth		/ /	
	10	Indicates sensitivity to body contact by quieting, crying, or body movement		/ /	
	11	Turns head toward nipple when his cheek is touched		/ /	
	12	Looks in direction of sound or changes body movement in response to sound		/ /	
	13	Looks at person attempting to gain his attention by talking or movement		/ /	
	14	Quiets or changes body movement in response to presence of person		/ /	
	15	Shows by body movements or cessation of crying, response to adult voice		/ /	
	16	Lifts and momentarily supports head when held with head at shoulder		/ /	
	17	Cries differentially due to different discomforts		/ /	
	18	Falls asleep at appropriate times		/ /	
	19	Thrusts arms about—no direction		/ /	
	20	Follows an object, visually, moved past midline of body		/ /	
	21	Smiles		/ /	
	22	Follows light with eyes, turning head		/ /	
	23	Follows sound, moving head		/ /	
	24	Regards hand		/ /	
	25	Kicks vigorously while on back		/ /	
	26	Opens mouth, begins sucking prior to nipple touching mouth		/ /	
	27	Maintains eye contact 3 seconds		/ /	

socialization

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
0-1	1	Watches person moving directly in line of vision		/ /	
	2	Smiles in response to attention by adult		/ /	
	3	Vocalizes in response to attention		/ /	
	4	Looks at own hands, often smiles or vocalizes		/ /	
	5	Responds to being in family circle by smiling, vocalizing, or ceasing to cry		/ /	
	6	Smiles in response to facial expression of others		/ /	
	7	Smiles and vocalizes to mirror image		/ /	
	8	Pats and pulls at adult facial features (hair, nose, glasses, etc.)		/ /	
	9	Reaches for offered object		/ /	
	10	Reaches for familiar persons		/ /	
	11	Reaches for, and pats at mirror image or another infant		/ /	
	12	Holds and examines offered object for at least a minute		/ /	
	13	Shakes or squeezes object placed in hand, making sounds unintentionally		/ /	
	14	Plays unattended for 10 minutes		/ /	
	15	Seeks eye contact often when attended for 2-3 minutes		/ /	
	16	Plays alone contentedly near adult activity 15-20 minutes		/ /	
	17	Vocalizes to gain attention		/ /	
	18	Imitates peek-a-boo		/ /	
	19	Claps hands, (pat-a-cake) in imitation of adult		/ /	
	20	Waves bye-bye in imitation of adult		/ /	
	21	Raises arms—"so big" in imitation of adult		/ /	
	22	Offers toy, object, bit of food to adult, but does not always release it		/ /	
	23	Hugs, pats, kisses familiar persons		/ /	
	24	Shows response to own name by looking or reaching to be picked up		/ /	
	25	Squeezes or shakes toy to produce sound in imitation		/ /	
	26	Manipulates toy or object		/ /	
	27	Extends toy or object to adult and releases		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	28	Imitates movements of another child at play		/ /	
1-2	29	Imitates adult in simple task (shakes clothes, pulls at bedding, holds silverware)		/ /	
	30	Plays with one other child, each doing separate activity		/ /	
	31	Takes part in game, pushing car or rolling ball with another child 2-5 minutes		/ /	
	32	Accepts parents' absence by continuing activities, may momentarily fuss		/ /	
	33	Actively explores his environment		/ /	
	34	Takes part in manipulative game (pulls string, turns handle) with another person		/ /	
	35	Hugs and carries doll or soft toy		/ /	
	36	Repeats actions that produce laughter and attention		/ /	
	37	Hands book to adult to read or share with him		/ /	
	38	Pulls at another person to show them some action or object		/ /	
	39	Withdraws hand, says "no-no" when near forbidden object with reminders		/ /	
	40	Waits for needs to be met when placed in high chair or on changing table		/ /	
	41	Plays with 2 or 3 peers		/ /	
	42	Shares object or food when requested with one other child		/ /	
	43	Greets peers and familiar adults when reminded		/ /	
2-3	44	Cooperates with parental request 50% of the time		/ /	
	45	Can bring or take object or get person from another room on direction		/ /	
	46	Attends to music or stories 5-10 minutes		/ /	
	47	Says "please" and "thank you" when reminded		/ /	
	48	Attempts to help parent with tasks by doing a part of the chore (holding dust pan)		/ /	
	49	Plays "dress-up" in adult clothes		/ /	
	50	Makes a choice when asked		/ /	
	51	Shows understanding of feelings by verbalizing love, mad, sad, laugh, etc.		/ /	
3-4	52	Sings and dances to music		/ /	
	53	Follows rules by imitating actions of other children		/ /	
	54	Greets familiar adults without reminder		/ /	

Socialization

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	55	Follows rules in group games led by adult		/ /	
	56	Asks permission to use toy that peer is playing with		/ /	
	57	Says "please" and "thank you" without reminder 50% of the time		/ /	
	58	Answers telephone, calls for adult or talks to familiar person		/ /	
	59	Will take turns		/ /	
	60	Follows rules in group games led by an older child		/ /	
	61	Cooperates with adult requests 75% of the time		/ /	
	62	Stays in own yard area		/ /	
	63	Plays near and talks with other children when working on own project (30 minutes)		/ /	
4-5	64	Asks for assistance when having difficulty (with bathroom or getting a drink)		/ /	
	65	Contributes to adult conversation		/ /	
	66	Repeats rhymes, song, or dances for others		/ /	
	67	Works alone at chore for 20-30 minutes		/ /	
	68	Apologizes without reminder 75% of the time		/ /	
	69	Will take turns with 8-9 other children		/ /	
	70	Plays with 2-3 children for 20 minutes in co-operative activity, (project or game)		/ /	
	71	Engages in socially acceptable behavior in public		/ /	
	72	Asks permission to use objects belonging to others 75% of the time		/ /	
5-6	73	States feelings about self: mad, happy, love		/ /	
	74	Plays with 4-5 children on co-operative activity without constant supervision		/ /	
	75	Explains rules of game or activity to others		/ /	
	76	Imitates adult roles		/ /	
	77	Joins in conversation at mealltime		/ /	
	78	Follows rules of verbal reasoning game		/ /	
	79	Comforts playmates in distress		/ /	
	80	Chooses own friends		/ /	
	81	Plans and builds using simple tools (inclined planes, fulcrum, lever, pulley)		/ /	

language

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
0-1	1	Repeats sound made by others		/ /	
	2	Repeats same syllable 2-3 times (ma. ma, ma)		/ /	
	3	Responds to gestures with gestures		/ /	
	4	Carries out simple direction when accompanied by gestures		/ /	
	5	Stops activity at least momentarily when told "no" 75% of the time		/ /	
	6	Answers simple questions with non-verbal response		/ /	
	7	Combines two different syllables in vocal play		/ /	
	8	Imitates voice intonation patterns of others		/ /	
	9	Uses single word meaningfully to label object or person		/ /	
	10	Vocalizes in response to speech of other person		/ /	
1-2	11	Says five different words (may use the same word to refer to different objects)		/ /	
	12	Asks for "more"		/ /	
	13	Says "all gone"		/ /	
	14	Follows 3 different one step directions without gestures		/ /	
	15	Can "give me" or "show me" upon request		/ /	
	16	Points to 12 familiar objects when named		/ /	
	17	Points to 3-5 pictures in a book when named		/ /	
	18	Points to 3 body parts on self		/ /	
	19	Says his own name or nickname upon request		/ /	
	20	Answers question "what's this?" with object name		/ /	
	21	Combines use of words and gestures to make wants known		/ /	
	22	Names 5 other family members including pets		/ /	
	23	Names 4 toys		/ /	
	24	Produces animal sound or uses sound for animal's name (cow is "moo-moo")		/ /	
	25	Asks for some common food items by name when shown (milk, cookie, cracker)		/ /	
	26	Asks questions by a rising intonation at end of word or phrase		/ /	
	27	Names 3 body parts on a doll or other person		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	28	Answers yes/no question with affirmative or negative reply		/ /	
2-3	29	Combines noun or adjective and noun in two word phrase (ball chair) (my ball)		/ /	
	30	Combines noun and verb in two word phrase (daddy go)		/ /	
	31	Uses word for bathroom need		/ /	
	32	Combines verb or noun with "there" "here" in 2 word utterance (chair here)		/ /	
	33	Combines 2 words to express possession (daddy car)		/ /	
	34	Uses "no" or "not" in speech		/ /	
	35	Answers question "what's ———doing?" for common activities		/ /	
	36	Answers "where" questions		/ /	
	37	Names familiar environmental sounds		/ /	
	38	Gives more than one object when asked using plural form (blocks)		/ /	
	39	Refers to self by own name in speech		/ /	
	40	Points to picture of common object described by its use (10)		/ /	
	41	Holds up fingers to tell age		/ /	
	42	Tells sex when asked		/ /	
	43	Carries out a series of two related commands		/ /	
	44	Uses "ing" verb form (running)		/ /	
	45	Uses regular plural forms (book/books)		/ /	
	46	Uses some irregular past tense forms consistently (went, did, was)		/ /	
	47	Asks question, "What's this (that)?"		/ /	
	48	Controls voice volume 90% of the time		/ /	
	49	Uses "this" and "that" in speech		/ /	
	50	Uses "is" in statements (this is ball)		/ /	
	51	Says "I, me, mine" rather than own name		/ /	
	52	Points to object that "is not ———" (is not a ball)		/ /	
	53	Answers "who" question with name		/ /	
	54	Uses possessive form of nouns (daddy's)		/ /	

language

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	55	Uses articles: the, a in speech		/ /	
	56	Uses some class names (toy, animal, food)		/ /	
	57	Says "can" and "will" occasionally		/ /	
	58	Describes items as open or closed		/ /	
3-4	59	Says "is" at beginning of questions when appropriate		/ /	
	60	Will attend for five minutes while story is read		/ /	
	61	Carries out series of two unrelated commands		/ /	
	62	Tells full name when requested		/ /	
	63	Answers simple "how" questions		/ /	
	64	Uses regular past tense forms (jumped)		/ /	
	65	Tells about immediate experiences		/ /	
	66	Tells how common objects are used		/ /	
	67	Expresses future occurrences with "going to," "have to," "want to"		/ /	
	68	Changes word order appropriately to ask questions (can I, does he)		/ /	
	69	Uses some common irregular plurals (men, feet)		/ /	
	70	Tells two events in order of occurrence		/ /	
4-5	71	Carries out a series of 3 directions		/ /	
	72	Demonstrates understanding of passive sentences (boy hit girl, girl was hit by boy)		/ /	
	73	Can find a <i>pair</i> of objects/pictures on request		/ /	
	74	Uses "could" and "would" in speech		/ /	
	75	Uses compound sentences (I hit the ball and it went in the road)		/ /	
	76	Can find <i>top</i> and <i>bottom</i> of items on request		/ /	
	77	Uses contractions can't, don't, won't		/ /	
	78	Can point out absurdities in picture		/ /	
	79	Uses words sister, brother, grandmother, grandfather		/ /	
	80	Tells final word in opposite analogies		/ /	
	81	Tells familiar story without pictures for cues		/ /	

self-help

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
0-1	1	Sucks and swallows liquid		/ /	
	2	Eats liquified foods, i.e. baby cereal		/ /	
	3	Reaches for bottle		/ /	
	4	Eats strained foods fed by parent		/ /	
	5	Holds bottle without help while drinking		/ /	
	6	Directs bottle by guiding it toward mouth or by pushing it away		/ /	
	7	Eats mashed table foods fed by parent		/ /	
	8	Drinks from cup held by parent		/ /	
	9	Eats semi-solid foods fed by parent		/ /	
	10	Feeds self with fingers		/ /	
	11	Holds and drinks from cup using two hands		/ /	
	12	Takes spoon filled with food to mouth with help		/ /	
	13	Holds out arms and legs while being dressed		/ /	
1-2	14	Eats table food with spoon independently		/ /	
	15	Holds and drinks from cup with one hand		/ /	
	16	Puts hands in water and pats wet hands on face in imitation		/ /	
	17	Sits on potty or infant toilet seat for 5 minutes		/ /	
	18	Puts hat on head and takes it off		/ /	
	19	Pulls off socks		/ /	
	20	Pushes arms through sleeves, legs through pants		/ /	
	21	Takes off shoes when laces are untied and loosened		/ /	
	22	Takes off coat when unfastened		/ /	
	23	Takes off pants when unfastened		/ /	
	24	Zips and unzips large zipper without working catch		/ /	
	25	Uses words or gestures indicating need to go to bathroom		/ /	
2-3	26	Feeds self using spoon and cup with some spilling		/ /	
	27	Takes towel from parent and wipes hands and face		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	28	Sucks liquid from glass or cup using straw		/ /	
	29	Scoops with fork		/ /	
	30	Chews and swallows only edible substances		/ /	
	31	Dries hands without help when given towel		/ /	
	32	Asks to go to bathroom, even if too late to avoid accidents		/ /	
	33	Controls drooling		/ /	
	34	Urinate or defecates in potty three times per week when placed on potty		/ /	
	35	Puts on shoes		/ /	
	36	Brushes teeth in imitation		/ /	
	37	Takes off simple clothing that has been unfastened		/ /	
	38	Uses bathroom for bowel movements. one daytime accident per week		/ /	
	39	Gets drink from faucet without help, when stool or steps are provided		/ /	
	40	Washes hands and face using soap when adult regulates water		/ /	
	41	Asks to go to bathroom during day in time to avoid accidents		/ /	
	42	Places coat on hook placed at child's height		/ /	
	43	Stays dry during naps		/ /	
	44	Avoids hazards such as sharp furniture corners, open stairs		/ /	
	45	Uses napkin when reminded		/ /	
	46	Stabs food with fork and brings to mouth		/ /	
	47	Pours from small pitcher (6-8 oz.) into glass without help		/ /	
	48	Unfastens snaps on clothing		/ /	
	49	Washes own arms and legs while being bathed		/ /	
	50	Puts on socks		/ /	
	51	Puts on coat, sweater, shirt		/ /	
	52	Finds front of clothing		/ /	
3-4	53	Feeds self entire meal		/ /	
	54	Dresses self with help on pullover shirts and all fasteners		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	55	Wipes nose when reminded		/ /	
	56	Wakes up dry two mornings out of seven		/ /	
	57	Males urinate in toilet standing up		/ /	
	58	Initiates and completes dressing and undressing except fasteners 75% of time		/ /	
	59	Snaps or hooks clothing		/ /	
	60	Blows nose when reminded		/ /	
	61	Avoids common dangers (i.e., broken glass)		/ /	
	62	Puts coat on hanger and replaces hanger on low bar with instructions		/ /	
	63	Brushes teeth when given verbal instructions		/ /	
	64	Puts on mittens		/ /	
	65	Unbuttons large buttons on button board or jacket placed on table		/ /	
	66	Buttons large buttons on button board or jacket placed on table		/ /	
	67	Puts on boots		/ /	
4-5	68	Cleans up spills, getting own cloth		/ /	
	69	Avoids poisons and all harmful substances		/ /	
	70	Unbuttons own clothing		/ /	
	71	Buttons own clothing		/ /	
	72	Clears place at table		/ /	
	73	Puts zipper foot in catch		/ /	
	74	Washes hands and face		/ /	
	75	Uses correct utensils for food		/ /	
	76	Wakes from sleep during night to use toilet or stays dry all night		/ /	
	77	Wipes and blows nose 75% of the time when needed without reminders		/ /	
	78	Bathes self except for back, neck, and ears		/ /	
	79	Uses knife for spreading soft toppings on toast		/ /	
	80	Buckles and unbuckles belt on dress or pants and shoes		/ /	
	81	Dresses self completely, including all front fastenings except ties		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	82	Serves self at table, parent holds serving dish		/ /	
	83	Helps set table by correctly placing plates, napkins, and utensils with verbal cues		/ /	
	84	Brushes teeth		/ /	
	85	Goes to bathroom in time, undresses, wipes self, flushes toilet, and dresses unaided		/ /	
	86	Combs or brushes long hair		/ /	
	87	Hangs up clothes on hanger		/ /	
	88	Goes about neighborhood without constant supervision		/ /	
	89	Laces shoes		/ /	
	90	Ties shoes		/ /	
5-6	91	Is responsible for one weekly household task and does it upon request		/ /	
	92	Selects appropriate clothing for temperature and occasion		/ /	
	93	Stops at curb, looks both ways, and crosses street without verbal reminders		/ /	
	94	Serves self at table and passes serving dish		/ /	
	95	Prepares own cold cereal		/ /	
	96	Is responsible for one daily household task (i.e., setting table, taking out trash)		/ /	
	97	Adjusts water temperature for shower or bath		/ /	
	98	Prepares own sandwich		/ /	
	99	Walks to school, playground, or store within two blocks of home independently		/ /	
	100	Cuts soft foods with knife (i.e., hot dogs, bananas, baked potato)		/ /	
	101	Finds correct bathroom in public place		/ /	
	102	Opens 1/2 pint milk carton		/ /	
	103	Picks up, carries, sets down cafeteria tray		/ /	
	104	Ties hood strings		/ /	
	105	Buckles own seat belt in car		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
0-1	1	Removes cloth from face, that obscures vision		/ /	
	2	Looks for object that has been removed from direct line of vision		/ /	
	3	Removes object from open container by reaching into container		/ /	
	4	Places object in container in imitation		/ /	
	5	Places object in container on verbal command		/ /	
	6	Shakes a sound making toy on a string		/ /	
	7	Puts 3 objects into a container, empties container		/ /	
	8	Transfers object from one hand to the other to pick up another object		/ /	
	9	Drops and picks up toy		/ /	
	10	Finds object hidden under container		/ /	
	11	Pushes 3 blocks train style		/ /	
	12	Removes circle from form board		/ /	
	13	Places round peg in pegboard on request		/ /	
	14	Performs simple gestures on request		/ /	
1-2	15	Individually takes out 6 objects from container		/ /	
	16	Points to one body part		/ /	
	17	Stacks 3 blocks on request		/ /	
	18	Matches like objects		/ /	
	19	Scribbles		/ /	
	20	Points to self when asked "Where's (<i>name</i>)?"		/ /	
	21	Places 5 round pegs in pegboard on request		/ /	
	22	Matches objects with picture of same object		/ /	
	23	Points to named picture		/ /	
	24	Turns pages of book 2-3 at a time to find named picture		/ /	
2-3	25	Finds specific book on request		/ /	
	26	Completes 3 piece formboard		/ /	
	27	Names 4 common pictures		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	28	Draws a vertical line in imitation		/ /	
	29	Draws a horizontal line in imitation		/ /	
	30	Copies a circle		/ /	
	31	Matches textures		/ /	
	32	Points to big and little upon request		/ /	
	33	Draws (+) in imitation		/ /	
	34	Matches 3 colors		/ /	
	35	Places objects in, on and under upon request		/ /	
	36	Names objects that make sounds		/ /	
	37	Puts together 4 part nesting toy		/ /	
	38	Names action pictures		/ /	
	39	Matches geometric form with picture of shape		/ /	
	40	Stacks 5 or more rings on a peg in order		/ /	
3-4	41	Names big and little objects		/ /	
	42	Points to 10 body parts on verbal command		/ /	
	43	Points to boy and girl on verbal command		/ /	
	44	Tells if object is heavy or light		/ /	
	45	Puts together 2 parts of shape to make whole		/ /	
	46	Describes two events or characters from familiar story or T.V. program		/ /	
	47	Repeats finger plays with words and actions		/ /	
	48	Matches 1 to 1 (3 or more objects)		/ /	
	49	Points to long and short objects		/ /	
	50	Tells which objects go together		/ /	
	51	Counts to 3 in imitation		/ /	
	52	Arranges objects into categories		/ /	
	53	Draws a V stroke in imitation		/ /	
	54	Draws a diagonal line from corner to corner of 4 inch square of paper		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	55	Counts to 10 objects in imitation		/ /	
	56	Builds a bridge with 3 blocks in imitation		/ /	
	57	Matches sequence or pattern of blocks or beads		/ /	
	58	Copies series of connected V strokes VVVVVVVV		/ /	
	59	Adds leg and/or arm to incomplete man		/ /	
	60	Completes 6 piece puzzle without trial and error		/ /	
	61	Names objects as same and different		/ /	
	62	Draws a square in imitation		/ /	
	63	Names three colors on request		/ /	
	64	Names three shapes, □, Δ, and ○		/ /	
4-5	65	Picks up specified number of objects on request (1-5)		/ /	
	66	Names five textures		/ /	
	67	Copies triangle on request		/ /	
	68	Recalls 4 objects seen in a picture		/ /	
	69	Names time of day associated with activities		/ /	
	70	Repeats familiar rhymes		/ /	
	71	Tells whether object is heavy or light (less than one pound difference)		/ /	
	72	Tells what's missing when one object is removed from a group of three		/ /	
	73	Names eight colors		/ /	
	74	Names penny, nickel and dime		/ /	
	75	Matches symbols (letters and numbers)		/ /	
	76	Tells color of named objects		/ /	
	77	Retells five main facts from story heard 3 times		/ /	
	78	Draws a man (head, trunk, 4 limbs)		/ /	
	79	Sings five lines of song		/ /	
	80	Builds pyramid of 10 blocks in imitation		/ /	
	81	Names long and short		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	28	Draws a vertical line in imitation		/ /	
	29	Draws a horizontal line in imitation		/ /	
	30	Copies a circle		/ /	
	31	Matches textures		/ /	
	32	Points to big and little upon request		/ /	
	33	Draws (+) in imitation		/ /	
	34	Matches 3 colors		/ /	
	35	Places objects in, on and under upon request		/ /	
	36	Names objects that make sounds		/ /	
	37	Puts together 4 part nesting toy		/ /	
	38	Names action pictures		/ /	
	39	Matches geometric form with picture of shape		/ /	
	40	Stacks 5 or more rings on a peg in order		/ /	
3-4	41	Names big and little objects		/ /	
	42	Points to 10 body parts on verbal command		/ /	
	43	Points to boy and girl on verbal command		/ /	
	44	Tells if object is heavy or light		/ /	
	45	Puts together 2 parts of shape to make whole		/ /	
	46	Describes two events or characters from familiar story or T.V. program		/ /	
	47	Repeats finger plays with words and actions		/ /	
	48	Matches 1 to 1 (3 or more objects)		/ /	
	49	Points to long and short objects		/ /	
	50	Tells which objects go together		/ /	
	51	Counts to 3 in imitation		/ /	
	52	Arranges objects into categories		/ /	
	53	Draws a V stroke in imitation		/ /	
	54	Draws a diagonal line from corner to corner of 4 inch square of paper		/ /	

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Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	55	Counts to 10 objects in imitation		/ /	
	56	Builds a bridge with 3 blocks in imitation		/ /	
	57	Matches sequence or pattern of blocks or beads		/ /	
	58	Copies series of connected V strokes VVVVVVVV		/ /	
	59	Adds leg and/or arm to incomplete man		/ /	
	60	Completes 6 piece puzzle without trial and error		/ /	
	61	Names objects as same and different		/ /	
	62	Draws a square in imitation		/ /	
	63	Names three colors on request		/ /	
	64	Names three shapes, □, Δ, and ○		/ /	
4-5	65	Picks up specified number of objects on request (1-5)		/ /	
	66	Names five textures		/ /	
	67	Copies triangle on request		/ /	
	68	Recalls 4 objects seen in a picture		/ /	
	69	Names time of day associated with activities		/ /	
	70	Repeats familiar rhymes		/ /	
	71	Tells whether object is heavy or light (less than one pound difference)		/ /	
	72	Tells what's missing when one object is removed from a group of three		/ /	
	73	Names eight colors		/ /	
	74	Names penny, nickel and dime		/ /	
	75	Matches symbols (letters and numbers)		/ /	
	76	Tells color of named objects		/ /	
	77	Retells five main facts from story heard 3 times		/ /	
	78	Draws a man (head, trunk, 4 limbs)		/ /	
	79	Sings five lines of song		/ /	
	80	Builds pyramid of 10 blocks in imitation		/ /	
	81	Names long and short		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	82	Places objects behind, beside, next to		/ /	
	83	Matches equal sets to sample of 1 to 10 objects		/ /	
	84	Names or points to missing part of pictured object		/ /	
	85	Counts by rote 1 to 20		/ /	
	86	Names first, middle and last position		/ /	
5-6	87	Counts up to 20 items and tells how many		/ /	
	88	Names 10 numerals		/ /	
	89	Names left and right on self		/ /	
	90	Says letters of alphabet in order		/ /	
	91	Prints own first name		/ /	
	92	Names five letters of alphabet		/ /	
	93	Arranges objects in sequence of width and length		/ /	
	94	Names capital letters of alphabet		/ /	
	95	Puts numerals 1 to 10 in proper sequence		/ /	
	96	Names position of objects first, second, third		/ /	
	97	Names lower case letters of alphabet		/ /	
	98	Matches capital to lower case letters of alphabet		/ /	
	99	Points to named numerals 1 to 25		/ /	
	100	Copies diamond shape		/ /	
	101	Completes simple maze		/ /	
	102	Names days of week in order		/ /	
	103	Can add and subtract combinations to three		/ /	
	104	Tells month and day of birthday		/ /	
	105	Sight reads 10 printed words		/ /	
	106	Predicts what happens next		/ /	
	107	Points to half and whole objects		/ /	
	108	Counts by rote 1 to 100		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
0-1	1	Reaches for object 6-9 inches in front of him		/ /	
	2	Grasps object held 3 inches in front of child		/ /	
	3	Reaches and grasps object in front of him		/ /	
	4	Reaches for preferred object		/ /	
	5	Puts objects in mouth		/ /	
	6	Head and chest supported on arms while on stomach		/ /	
	7	Holds head and chest erect supported on one arm		/ /	
	8	Feels and explores object with mouth		/ /	
	9	Turns from stomach to side, maintains position 50% of the time		/ /	
	10	Rolls from stomach to back		/ /	
	11	Moves forward one body length on stomach		/ /	
	12	Rolls from back to side		/ /	
	13	Turns from back to stomach		/ /	
	14	Pulls to sitting position when grasping adult's fingers		/ /	
	15	Turns head freely when body is supported		/ /	
	16	Maintains sitting position for two minutes		/ /	
	17	Puts down one object deliberately to reach for another		/ /	
	18	Picks up and drops object on purpose		/ /	
	19	Stands with maximum support		/ /	
	20	Bounces up and down in standing position while being supported		/ /	
	21	Crawls one body length to obtain object		/ /	
	22	Sits self supported		/ /	
	23	From sitting position, turns to hands and knees position		/ /	
	24	Moves from stomach to sitting position		/ /	
	25	Sits without hand support		/ /	
	26	Flings objects haphazardly		/ /	
	27	Rocks back and forth on hands and knees		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	28	Transfers object from one hand to the other in sitting position		/ /	
	29	Retains two one-inch cubes in one hand		/ /	
	30	Pulls self to on-knees position		/ /	
	31	Pulls self to standing position		/ /	
	32	Uses pincer grasp to pick up object		/ /	
	33	Creeps		/ /	
	34	Reaches with one hand from creep position		/ /	
	35	Stands with minimum support		/ /	
	36	Licks food from around mouth		/ /	
	37	Stands alone for one minute		/ /	
	38	Dumps object from receptacle		/ /	
	39	Turns pages of book, several at a time		/ /	
	40	Scoops with spoons or shovel		/ /	
	41	Puts small objects in container		/ /	
	42	Lowers self from standing to sitting position		/ /	
	43	Claps hands		/ /	
	44	Walks with minimum aid		/ /	
	45	Takes a few steps without support		/ /	
1-2	46	Creeps upstairs		/ /	
	47	Moves from sitting to standing position		/ /	
	48	Rolls a ball in imitation		/ /	
	49	Climbs into adult chair, turns and sits		/ /	
	50	Puts 4 rings on peg		/ /	
	51	Removes 1" pegs from pegboard		/ /	
	52	Puts 1" pegs in pegboard		/ /	
	53	Builds tower of 3 blocks		/ /	
	54	Marks with crayon or pencil		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	55	Walks independently		/ /	
	56	Creeps down stairs, feet first		/ /	
	57	Seats self in small chair		/ /	
	58	Squats and returns to standing		/ /	
	59	Pushes and pulls toys while walking		/ /	
	60	Uses rocking horse or rocking chair		/ /	
	61	Walks upstairs with aid		/ /	
	62	Bends at waist to pick up objects without falling		/ /	
	63	Imitates circular motion		/ /	
2-3	64	Strings 4 large beads in two minutes		/ /	
	65	Turns door knobs, handles, etc.		/ /	
	66	Jumps in place with both feet		/ /	
	67	Walks backwards		/ /	
	68	Walks downstairs with aid		/ /	
	69	Throws ball to adult 5 feet away without adult moving feet		/ /	
	70	Builds tower of 5-6 blocks		/ /	
	71	Turns pages one at a time		/ /	
	72	Unwraps small object		/ /	
	73	Folds paper in half in imitation		/ /	
	74	Takes apart and puts together snap-together toy		/ /	
	75	Unscrews nesting toys		/ /	
	76	Kicks large stationary ball		/ /	
	77	Rolls clay balls		/ /	
	78	Grasps pencil between thumb and forefinger, resting pencil on third finger		/ /	
	79	Forward somersault with aid		/ /	
	80	Pounds 5 out of 5 pegs		/ /	
3-4	81	Puts together 3 piece puzzle or formboard		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	82	Snips with scissors		/ /	
	83	Jumps from height of 8 inches		/ /	
	84	Kicks large ball when rolled to him		/ /	
	85	Walks on tiptoe		/ /	
	86	Runs 10 steps with coordinated, alternating arm movement		/ /	
	87	Pedals tricycle five feet		/ /	
	88	Swings on swing when started in motion		/ /	
	89	Climbs up and slides down 4-6 foot slide		/ /	
	90	Somersaults forward		/ /	
	91	Walks up stairs, alternating feet		/ /	
	92	Marches		/ /	
	93	Catches ball with two hands		/ /	
	94	Traces templates		/ /	
	95	Cuts along 8" straight line within 1/4" of line		/ /	
4-5	96	Stands on one foot without aid 4-8 seconds		/ /	
	97	Runs changing direction		/ /	
	98	Walks balance beam		/ /	
	99	Jumps forward 10 times without falling		/ /	
	100	Jumps over string 2 inches off the floor		/ /	
	101	Jumps backward six times		/ /	
	102	Bounces and catches large ball		/ /	
	103	Makes clay shapes put together with 2 to 3 parts		/ /	
	104	Cuts along curved line		/ /	
	105	Screws together threaded object		/ /	
	106	Walks downstairs alternating feet		/ /	
	107	Pedals tricycle, turning corners		/ /	
	108	Hops on one foot 5 successive times		/ /	

Age Level	Card	Behavior	Entry Behavior	Date Achieved	Comments
	109	Cuts out 2-inch circle		/ /	
	110	Draws simple recognizable pictures such as house, man, tree		/ /	
	111	Cuts out and pastes simple shapes		/ /	
5-6	112	Prints capital letters, large, single, anywhere on paper		/ /	
	113	Walks balance board forward, backward and sideways		/ /	
	114	Skips		/ /	
	115	Swings on swing initiating and sustaining motion		/ /	
	116	Spreads fingers, touching thumb to each finger		/ /	
	117	Can copy small letters		/ /	
	118	Climbs step ladders or steps ten feet high to slide		/ /	
	119	Hits nail with hammer		/ /	
	120	Dribbles ball with direction		/ /	
	121	Colors, remaining within lines 95%		/ /	
	122	Can cut picture from magazine or catalog without being more than 1/4" from edge		/ /	
	123	Uses pencil sharpener		/ /	
	124	Copies complex drawings		/ /	
	125	Tears simple shapes from paper		/ /	
	126	Folds paper square two times on diagonal in imitation		/ /	
	127	Catches soft ball or bean bag with one hand		/ /	
	128	Can jump rope by self		/ /	
	129	Hits ball with bat or stick		/ /	
	130	Picks up object from ground while running		/ /	
	131	Skates forward 10 feet		/ /	
	132	Rides bicycle		/ /	
	133	Slides on sled		/ /	
	134	Walks or plays in water waist-high in swimming pool		/ /	
	135	Steers wagon, propelling with one foot		/ /	

Appendix 5: Carer Information Letter

- English Language Original
- Hindi Version
- Marathi Version

INFORMATION FOR CARERS ON THE NUTRITION AND DISABILITY PROJECT

This project is being conducted by the Karuna Sudan Centre and the Institute of Child Health, England.

The project is looking at nutrition and disability.

We would like to weigh and measure your child. We would also like to take a small blood sample from your child and see whether she/he has adequate amounts of vitamins and minerals.

All children participating in the study with low vitamins and minerals will receive supplements. We will offer nutritional advice to all parents.

Carers of children with disabilities and who have problems with feeding will be invited to attend workshops to learn feeding skills and discuss the problems.

Carers of children with disabilities will be invited to discuss day to day care with staff on the project.

If you take part in the project, you are free to withdraw at any time without explanation.

If you do not take part, your child will continue to receive services currently used.

The results of the project will be discussed with you by staff on the project.

यह प्रकल्प करुणा सदन, धारावी और बालशौचालय केन्द्र, लंदन की तरफ से आयोजित किया हुआ है।

यह प्रकल्प दो महत्वपूर्ण मुद्दों पर आधारित है :-

* सकस आहार (पोष्टिक)

* विकासंगता

यहाँ हम आपके बच्चों को वजन और खून की जांच करेगे और यह देखने वाले हैं कि यदि उनमें उनके लिए आवश्यक जीवितत्व और खनिजपदार्थ की मात्रा है कि नहीं।

इस प्रकल्प में शामिल होने वाले बच्चों में जिनमें जीवितत्व और खनिजपदार्थों की कमी है, उनको हम आवश्यक स्वास्थ्य टॉनिक उपलब्ध करके देगे। उनके माता पिता को पोष्टिक आहार के बारे में जानकारी देगे।

माता पिताओं के लिए आयोजित कार्यशाला में जिन विकलांग बच्चों को रखरखने की समस्या आती है, उनको यहाँ आमंत्रित करके, उसके बारे में सिखाया जाएगा और उनको पोष्टिक अन्नपदार्थ घर लेकर जाने के लिए दिए जाएगे।

विकलांग बच्चों के माता पिताओं को विकासंगता के बारे में लिए जानेवाली सावधानियों के बारे में करुणा सदन के कर्मचारियों से सलह दी जाएगी।

यदि आप इस प्रकल्प में शामिल नहीं हुए, तो भी करुणा सदन की तरफ से जानेवाली सुविधाएँ जारी रहेंगी।

अगर आप इस प्रकल्प में भाग लिया है तो, आप जब चाहें तब बीच में छोड़कर जा सकते हैं।

इस प्रकल्प के नतीजों पर आप करुणा सदन के कर्मचारियों से सलह मशवरा कर सकते हैं।

- हा प्रकल्प करुणा सदन धारावी आणि थाल आरोग्य केंद्र, लंडन यांच्यामार्फत राबविण्यात येत आहे
- ह्या प्रकल्पाचे महत्वाचे दोन मुद्दे म्हणजे
1) सकस आहार , 2) अपंगात्व
- आम्ही ह्या ठिकाणी आपल्या मुलांचे वजन व त्यांच्या रक्ताची तपासणी करून त्यांच्यांमध्ये त्यांना आवश्यक इतके जीवनसत्व आणि स्वनिज आहे की नाही हे पाहणार आहोत.
- ह्या प्रकल्पासह्ये सहभागी असणाऱ्यांपैकी ज्या मुलांमध्ये जीवनसत्वे व स्वनिजे यांची कमतरता आढळेल त्यांना आम्ही आवश्यक असे आरोग्य टॉनिक देणार आहोत. त्यांच्या पालकांनाही सकस आहार बदल मार्गदर्शन करणार आहोत.
- पालकांसाठी द्यावात येणाऱ्या कार्यशाळेत ज्या अपंगा मुलांना अन्न भरविण्याच्या समस्या येतात, त्यांना येशे असंत्रित करून अन्न भरविण्याबद्दल मार्गदर्शन करण्यात येईल. आणि त्यांना सकस आहारयुक्त अन्न पदार्थही घरी घेऊन जाण्यास देण्यात येतील.

- अपंग मुलांच्या पालकाना अपंगत्वाबाबत द्यावयाच्या काळजीची माहिती ही करणे। सदन येथील कर्मचाऱ्यांकडून पुरविणी जाईल.
- जरी आपण ह्या प्रकल्पात सहभागी नाहीत, तरीही करुणासदन नफे पुरविण्यात येणाऱ्या भुविद्या कायम राहतील.
- जर तुम्ही या प्रकल्पात भाग घेतला, तरी तुम्हाला मदत कधी ही सोडून जाण्याची मुभा देण्यात येईल.
- या प्रकल्पाच्या निष्कर्षावरून करुणा सदनाच्या कर्मचाऱ्यांकडून तुमच्याशी चर्चा करण्यात येईल.

Appendix 6: Pre-Workshop Questionnaire

DISABILITY AND NUTRITION PROJECT: PRE-WORKSHOP QUESTIONNAIRE

CHILD ID	
CHILD NAME	
CHILD AGE	

DATE OF VISIT	
INTERVIEWEE (Relationship to child)	
INTERVIEWER	

PHOTOGRAPH TAKEN	
FILM TAKEN (and note meal time)	

A: FEEDING PRACTICES AND EXPERIENCES.

Reported answers from interviewee.

1. DOES THE CHILD HAVE ANY FEEDING DIFFICULTIES?

SEVERE

NONE

2. IS YOUR CHILD AN INDEPENDENT FEEDER? (tick appropriate box)

Yes	
Semi-independent	
No	

3. IS CHILD FED BY HAND OR IS A SPOON USED? (tick appropriate box)

Mainly spoon fed	
Mainly hand fed	

IS A CUP USED FOR DRINKING?

CUP	
BOWL	
BOTTLE	
OTHER (please state)	

4. APPETITE AND THIRST: (To be asked regarding case child, interviewee and sibling child) (tick appropriate box)

CASE CHILD	Good	Moderate	Poor
Appetite			
Thirst			

INTERVIEWEE	Good	Moderate	Poor
Appetite			
Thirst			

SIBLING (in phase 1)	Good	Moderate	Poor
Appetite			
Thirst			

5. DO THESE PROBLEMS EVER ARISE:

	A lot	Some	Rare	Never
Choking				
Coughing				
Vomiting				
Drooling				
Constipation				
Diarrhea				

6. How long does your child take to finish a meal?

LONG

SHORT

7. POSITION AND MEAL TIME INFORMATION:

a.

Where does the child usually eat?		
Who usually feeds the child?		
Where does the feeder sit?		
How is the child positioned at meal times? Is any support given to the child during feeding?		

b.

Are the other siblings present at meal times?	
Are any of the other siblings dependent feeders? (If so is one person feeding all children)	

c.

Do you feel you have enough time to feed the child?	
---	--

d.

How many meals are given to the child per day?	
--	--

8. ADDITIONAL INFORMATION:

Does the child have any particular likes / dislikes?	
Does the child ever refuse food?	
Are there some foods the child finds more manageable to eat? Do you prepare any special food items (mashed, pureed, etc)?	
Are there food items you believe to be good/bad for the child?	
Has your child ever received any feeding interventions? (apart from this project)	
	Vitamins
	Food
	Advice
Do you have any other concerns about your child's weight, eating habits, or health?	
Additional comments made by interviewee?	

B: FUNCTIONAL FEEDING ASSESSMENT (DJ Kenny *et al*, 1989)

To be completed by observation. An evaluation of oral-motor skills during specific feeding tasks. The person is tested in his/her typical feeding position. Be cautious when introducing food or liquid into the mouth, particularly if there is a history of choking. Swallowing and Associated movements can be assessed during each of the following tasks, or, if necessary, repeat the activities to obtain information. (tick appropriate boxes).

FOOD GIVEN:	
DRINK GIVEN:	

1. SPOON FEEDING (or by hand)

Use of a soft consistency of food. Observe for normal pattern and associated movement.

Normal Pattern	Adequate	Poor	Absent	Unable to determine
Holds head steady, slightly forward to midline.				
Brings head forward to spoon				
Opens mouth to sight of spoon				
Keeps tongue still on floor of mouth				
Brings upper lip down and forward over spoon				
Holds jaw stable				
Pulls lower lip inward under spoon				
Clears excess food off lips with tongue				
Keeps lips closed during swallowing				

2. BITING

Food should be placed between the grinding surfaces of the molars. Use a "biscuit and banana". Observe for normal pattern and associated movement.

Normal Pattern	Adequate	Poor	Absent	Unable to determine
Holds head steady, slightly forward to midline.				
Grades mouth opening				
Keeps tongue still on floor of mouth				
Brings upper and lower molars together				
Exhibits controlled (graded) bite				

Normal Pattern	Adequate	Poor	Absent	Unable to determine
Breaks through biscuit				
Breaks through banana				

3. CHEWING

Normal Pattern	Adequate	Poor	Absent	Unable to determine
Holds head steady, slightly forward to midline.				
Moves head from side to side with tongue (rotary jaw movement)				
Forms adequate bolus				

4. CUP DRINKING

Use a liquid familiar to the child and usual cup. Observe for normal pattern and associated movement.

Normal Pattern	Adequate	Poor	Absent	Unable to determine
Holds head steady, slightly forward to midline.				
Brings head forward to cup				
Forms lip seal on cup				
Keeps tongue within oral cavity				
Keeps jaw and lower lip stable				
Moves upper lip to draw in liquid				
Able to take sequence of sips				
Adjusts rate of inflow by pulling back				

5. SWALLOWING

Repeat any of the previous tasks to facilitate this section.

Normal Pattern	Adequate	Poor	Absent	Unable to determine
Holds head steady, slightly forward to midline.				
Transports solids to back of mouth				
Keeps lips closed while swallowing solids				
Transports liquids to back of mouth				

Normal Pattern	Adequate	Poor	Absent	Unable to determine
Keeps lips closed while swallowing liquids				

6. IF PRESENT SPECIFY AMOUNT OF:

	Mild	Moderate	Severe
Coughing			
Choking			
Food Loss			
Liquid Loss			

7. DROOLING DURING EATING:

Absent	
Excess saliva in mouth	
Wet lips	
Wet chin to overt drooling	

C: WORKSHOPS

Give interviewee description of workshops.

Will you be able to participate in workshops?	
---	--

THANK YOU FOR YOUR TIME.

Appendix 7: Description of Films and Film Observation Checklist

- Description of films taken
- Information for observers
- Observation Checklist

Description of Films Taken

- Films were taken of 10 children eating usual foods in a familiar environment. The films were taken between January and March 2000.
- Information on feeding independence in column 1 is filled in according to the carer's response in the pre-workshop questionnaire.
- Running time of film: 1hr 35min.

CHILD	MEAL	PEOPLE PRESENT
FILM NO: 1 ID: 417 AGE: 7y DISABILITY: Physical, speech FEEDING IND: Semi-independent	<ul style="list-style-type: none"> • Lunch (after school) • Home • Rice, veg, chappati 	AKY, VJ, mother , neighbour
FILM NO: 2 ID: 414 AGE: 7y DISABILITY: CP/MR FEEDING IND: Dependent	<ul style="list-style-type: none"> • Milk time, (milk given regularly thro' day). • Home with mother • Warm milk 	AKY, VJ, mother and friend (TV on in background)
FILM NO: 3 ID: (m) 369 AGE: 3y DISABILITY: CP FEEDING IND: Dependent	<ul style="list-style-type: none"> • Lunch • Home with grandmother • Baby formula, water 	AKY, VJ, grandmother (maternal)
FILM NO: 5 ID: 411 AGE: 7y DISABILITY: CP FEEDING IND: Dependent	<ul style="list-style-type: none"> • Milk time, (milk given regularly thro' day-every 2 or 3hours). • Home with family • Sister is giving milk • Cold milk 	AKY, VJ, mother, sister, family members
FILM NO: 6 ID: 459 AGE: 3y DISABILITY: CP	<ul style="list-style-type: none"> • Lunch • School • Fed by sister (4.5y) • Idlee, coconut chutney, water 	AKY, class

FEEDING IND: Dependent		
FILM NO: 7 ID: 124 AGE: 4y DISABILITY: CP FEEDING IND: Semi-independent	<ul style="list-style-type: none"> • Lunch • School • Fed by helper • Idlee, coconut chutney 	AKY, class
FILM NO: 8 ID: 360 AGE: 7y DISABILITY: CP/MR FEEDING IND: independent	<ul style="list-style-type: none"> • Lunch • School • Fed by helper • Idlee, water 	AKY, class
FILM NO: 9 ID: 456 AGE: 7y DISABILITY: CP FEEDING IND: Dependent	<ul style="list-style-type: none"> • Snack • School • Banana (from home), water 	AKY, class
FILM NO: 10 ID: 127 AGE: 5y DISABILITY: CP FEEDING IND: Dependent	<ul style="list-style-type: none"> • Lunch • Omelette, rice, water • Fed by mother 	AKY, mother, neighbour child

Feeding Observations

The following films were taken as part of the project investigating the nutritional status of disabled children living in a Mumbai slum.

To date the project results indicate that some disabled children do have a worse nutritional status than non-disabled peers do. This may in part be related to feeding problems, the knowledge of feeding skills and the perception of carers.

The films were taken as illustrative examples of feeding practice of disabled children in the area. They contributed towards the planning of workshops on improving nutritional status and feeding skills. Detailed questionnaires on feeding were completed including both carer and researcher observations. The children in these films represent 13% of the total sample studied. We would like to have additional observer notes as an objective measure of reliability.

Ten short films were taken of children eating a typical meal or snack in a familiar environment. The children are mainly diagnosed with cerebral palsy. Each film need only be watched for approximately 10 minutes and observations can be recorded in the observation schedule attached.

None of the children have had any specialist interventions and are unlikely to. The films and guidance were made primarily for local community workers and carers. The observation schedule may therefore appear a little simplified.

Thank you for your time.

Observation Schedule for Observer's initials:

✓ or X	Method	Appropriate? y/n	Any Comments:
<input type="checkbox"/>	Child is being fed by parent / other sitting / standing beside in front of behind child other.....		
<input type="checkbox"/>	Child is given drink <ul style="list-style-type: none"> • bottle • cup / beaker • straw • other 		
<input type="checkbox"/>	Child feeds independently <ul style="list-style-type: none"> • finger feeding • spoon feeding • cup drinking 		
<input type="checkbox"/>	Texture of child's food <ul style="list-style-type: none"> • smooth puree • lumpy puree • chewable solid • bite/chew solids 		
<input type="checkbox"/>	Texture of child's drink <ul style="list-style-type: none"> • thin • thickened 		

✓ or X	Method	Appropriate? y/n	Any Comments:
<input type="checkbox"/>	Difficulties observed <ul style="list-style-type: none"> • coughing • choking • gagging • aversion -turning away 		
<input type="checkbox"/>	Loss of food or drink anteriorally: <ul style="list-style-type: none"> • food • liquid 		
<input type="checkbox"/>	Child has excessive dribbling / drooling?		
<input type="checkbox"/>	Child's feeding position is visible: <ul style="list-style-type: none"> • supine • upright • semi-upright 		
<input type="checkbox"/>	Child is sitting: <ul style="list-style-type: none"> • in a chair • in parents lap • on the ground / mat 		
<input type="checkbox"/>	Head position is visible: <ul style="list-style-type: none"> • chin tucked • head tilted back • <i>normal</i> 		

✓ or X	Method	Appropriate? y/n	Any Comments:
<input type="checkbox"/>	The food appears to be part of the child's normal diet		
<input type="checkbox"/>	The food appears to be part of a special diet		
<input type="checkbox"/>	Child eats at the family mealtime i.e. they eat with other family members		
<input type="checkbox"/>	Child eats alone		
<input type="checkbox"/>	Child eats at home		
<input type="checkbox"/>	Child eats at school		
<input type="checkbox"/>	Child uses left hand during mealtime	Functionally Appropriate: Y or N (circle)	
<input type="checkbox"/>	Child is encouraged to have his / her meal by the parent / carer through: <ul style="list-style-type: none"> • verbal cues • physical prompts e.g. touch 		
<input type="checkbox"/>	Carer wipes mouth after meal		
<input type="checkbox"/>	Child self-wipes after meal		

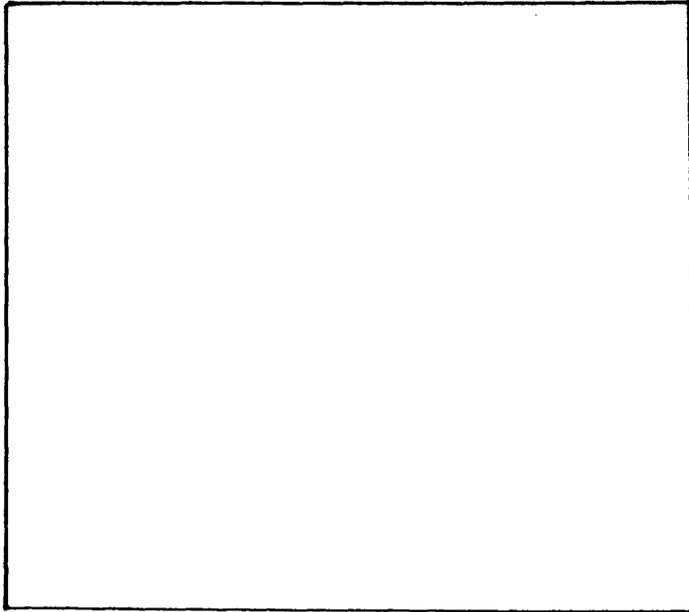
✓ or X	Method	Appropriate? y/n	Any Comments:
<input type="checkbox"/>	Child communicates <ul style="list-style-type: none"> • verbally • gesturally • non-verbal other..... 		

Additional Suggestions

Appendix 8: The Workshop Manual

- Please see supplement with thesis for the final version of the manual distributed in Dharavi.
- Workshop Manual: English layout guide enclosed.

Feeding Disabled Children.



A Guide for carers living in Dharavi.

CICH.

SSI.

Contents

1. Introduction
2. Position
3. Nutritional Advice
4. Management of Eating Difficulties
5. Management of Drinking Difficulties
6. Independent feeding
7. Advice for Visually Impaired Children.
8. Oral Hygiene.
9. Further Information.

1. INTRODUCTION

Why we need to develop good feeding skills?

1) It is important for a healthy life.

2) Good feeding skills are useful for learning other skills, eg: speech
physical development

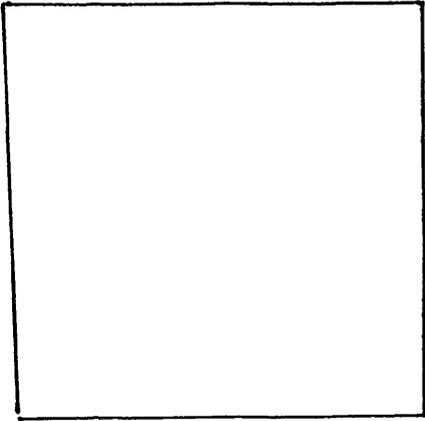
• Disabled children have eating and drinking problems for many reasons.

This book will help solve problems in feeding.

- The disabled children need the same food as other children.
- We must encourage the disabled child to eat to prevent sickness and malnutrition.
- Malnourished children do not grow well and are underweight. They have less energy to play and learn and are more likely to become sick.
- Learning to feed a child with eating problems makes the child happier and easier to care for.

2 Position.

The child should be fed in an upright position.

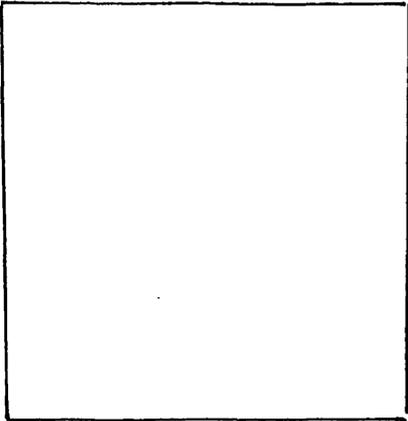


Place arm around neck.

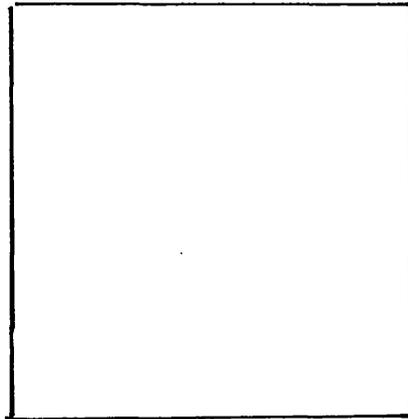
Head is kept straight and facing forward.

Ensure child is fully supported.

Never feed your child when he is lying down - there is a danger of choking.



If possible, encourage the child to sit independently. He can lean against a wall and be supported by cushions.



This is a suitable position if child has better head control.

- Only when you and the child are comfortable should feeding begin.
- Do not let head tilt back. It makes swallowing difficult. Child may choke.

3. Nutritional Advice

Vitamin/ mineral	function	foods
A	Eye sight. Increases resistance to infection	Carrots Tomatoes Peas Prunes.
D	Important for healthy bones and teeth.	"Sunlight" Fish
C	Increases resistance to infection.	Green leafy vegetables Tomatoes Potatoes
Iron	Important for blood and muscles. Prevents tiredness.	Green leafy vegetables Dhals.

- Wash hands and utensils before preparing foods.
- Wash vegetables - then chop - \therefore you do not lose vitamins.
- Keep lids on pots when boiling vegetables so you do not lose vitamins.
- Make foods richer with vitamins, eg: green leaves in chapatis.
- Remember : Vitamin D we obtain from sunlight. All children need to spend time in sunshine. Even if your child is immobile allow him to spend 10 minutes everyday in the sun.
- Special foods : children who have difficulty biting, chewing and swallowing may find some foods difficult to manage. They must be encouraged to eat solids and not only liquids.

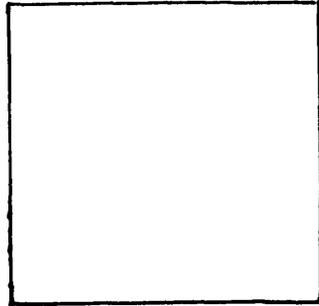
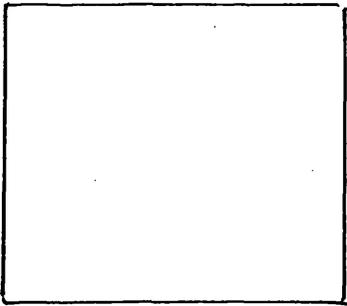
eg:- Suji and milk
Bread and milk
Mashed potato
Mashed banana
Kichadi.

Offer a little everyday.

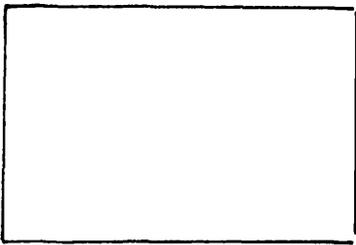
- Even if child is sick, encourage him to eat. If child refuses try again later. A sick child must also eat to get better.
- Involve whole family. Good nutrition is important for pregnant mother, siblings, etc.
- Deworming twice a year. This is FREE from BMC hospitals (mebex).

4. Management of Eating Difficulties.

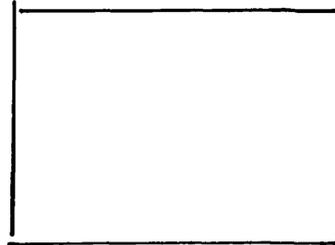
- Sensitivity.



- Jaw Control.

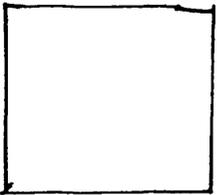


Sitting next to child.

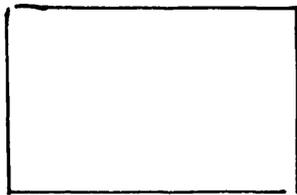


Sitting facing the child.

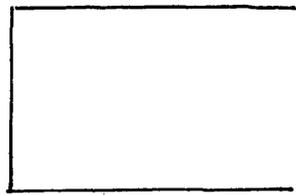
- Spoon and Hand feeding.



Correct way. ✓

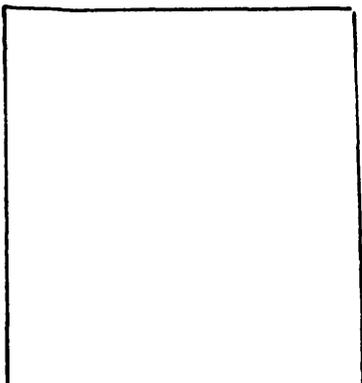


Wrong. X



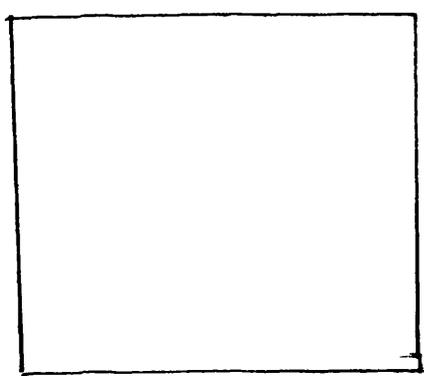
Wrong. X

- Tongue Thrust.



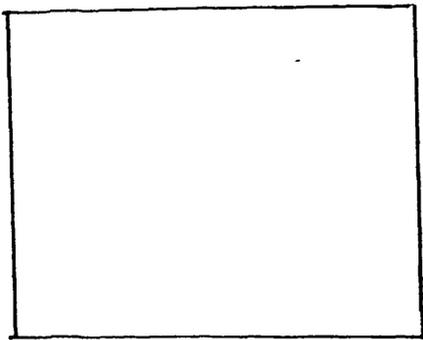
A good example.

Biting

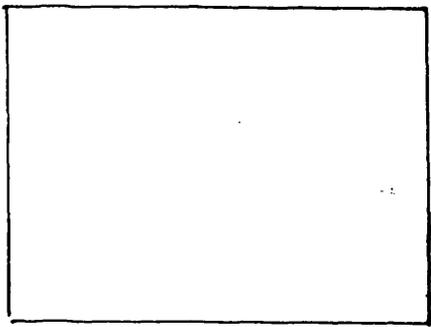


Start with soft food.
Place food between teeth.
Close mouth gently.
Do not push head back.

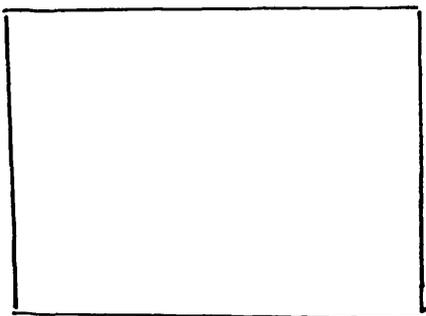
Chewing



Help child to chew.
Place food in side of mouth.

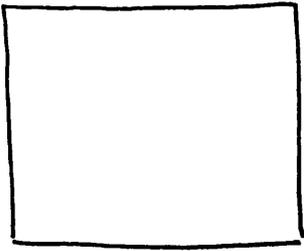


Practice chewing.



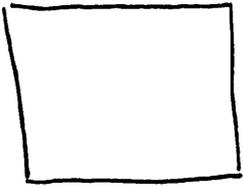
- To encourage swallowing stroke throat gently.

Drooling.



Mouth must be wiped.
Head in good position.

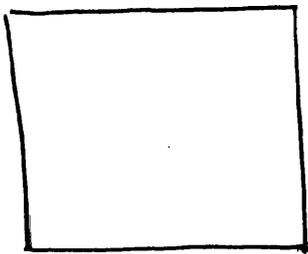
Encourage self wiping.



Remind child to press lips together during
swallowing.

Never tilt head back!

• Choking



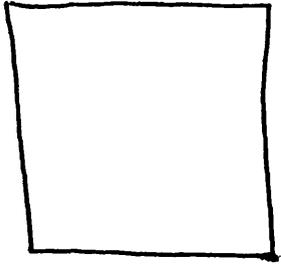
If child chokes bring head, shoulders and body
forward. Never tap child on back or head. It makes
it worse. Check and clear obstructions in mouth.

• Vomiting

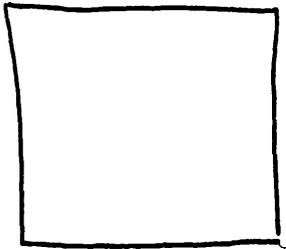
- Do not force a child to eat if he is not hungry.
- Encourage child to eat later.
- Encourage good chewing.
- Only give small amounts of food for each mouthful.

"At the end of the meal ensure no food is left in mouth. Encourage
rinse or drinking water."

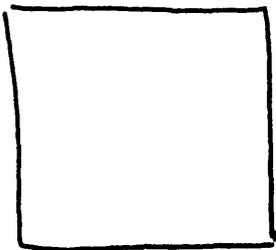
5. Management of Drinking Difficulties.



Good position
Support if necessary.



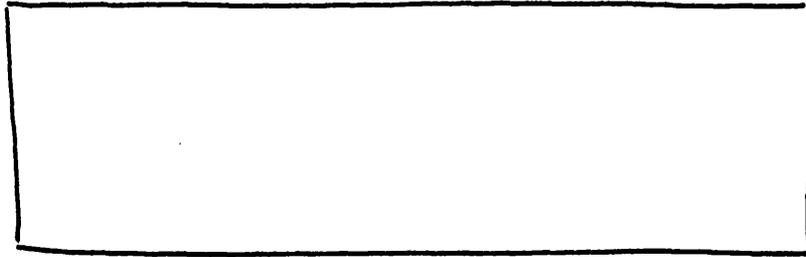
Encourage lips to close around rim if necessary.



A good independent position.

6. Independent Feeding.

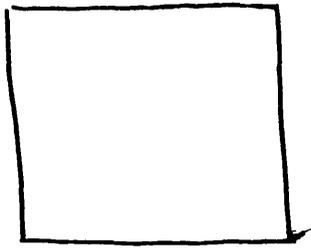
This is important for the future.



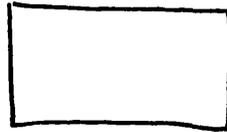
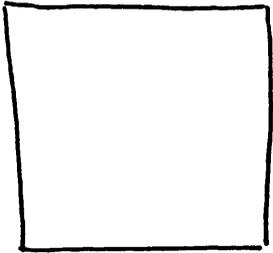
Sit comfortably. Give support only when needed. Help less each time. Praise him when he has done well. Let him use any hand.

- Put food in bite size pieces if it helps child.
- Keep hands clean of child for hygiene. Keep hair back \therefore child can clearly see food.

7. Advice for Visually Impaired Children.



Guide your child



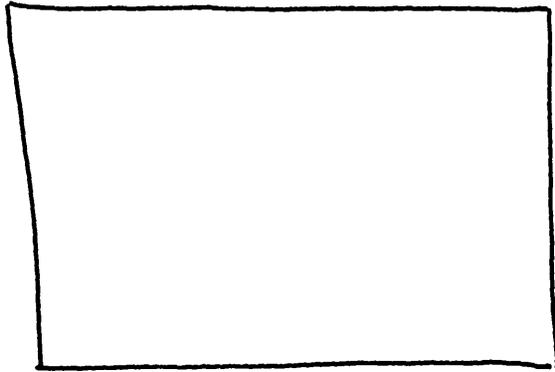
- Encourage step by step independence.

8. Oral Hygiene.

It is very important to keep teeth clean.

If we feed a lot of sweet food the teeth may rot unless kept clean

Dribbling can reduce moisture in mouth which helps clean teeth.



9. Further Information.

Useful free services :

- 1) Cooking Workshops.
 - UHC, 60ft Rd, Dharavi.
- 2) Therapy.
 - UHC, 60ft Rd, Dharavi
 - Sion Hospital
- 3) Karuna Sadan Centre / SSI
- 4) UGAM Aganwadis / SSI
 - i) Rajiv Gandhi Ng.
 - ii) " " "
 - iii) Kalakita Ng
 - iv) Naik Ng
 - v) Prem Ng.

Appendix 9: Post-Workshop Questionnaire

POST-WORKSHOP QUESTIONNAIRE

CHILD ID	
INTERVIEWEE	
DATE OF INTERVIEW	
INTERVIEWER	

SECTION A:

1. Do you feel the workshops were held at a suitable time in the day? (Tick box)

YES	
NO (if no-WHEN?)	

2. Did you feel the duration of the workshop was: (Tick box)

TOO LONG	
TOO SHORT	
OK	

SECTION B:

1. What do you remember from the workshops? (Do not offer options. Tick box)

ITEM PRESENTED:	REMEMBERED?	COMMENTS (if any made by interviewee)
POSITION		
NUTRITION		
EATING DIFFICULTIES		
DRINKING DIFFICULTIES		
INDEPENDENT FEEDING		
ADVICE FOR VISUALLY IMPAIRED CHILDREN		
ORAL HYGIENE		
COOKING		
GUIDE BOOK		
OTHER		

SECTION C:

1. Did you learn any useful information? Can you give examples?

--

2. Did you understand the advice given? (Tick box and add any comments if any)

YES	
NO	
SOME	

3. Was the advice applicable at home? (Tick box and add any comments if any)

YES	
NO	
SOME	

4. Are you now more comfortable feeding your child after the workshop? (Tick box or add comment)

YES	
NO	
THE SAME AS BEFORE	
OTHER COMMENTS	

5. Do you feel your child has benefited from you attending the workshop? (Tick box and add comment if any)

NO	
SOME	
A LOT	

6. Is there any other information, which should have been included in the workshop?

YES (if yes- WHAT?)	
NO	

7. Did you ask for home visits? If so did you find these useful?

YES (COMMENTS)	
NO	

SECTION D:

1. Was the guidebook useful? If so can you describe why?

--

2. Did the guidebook contain easy-to-follow information?

YES	
NO	

3. Was the guidebook: (Tick box)

TOO LONG	
TOO SHORT	
OK	

4. Are you able to read the information yourself or do you have help from someone?

--

5. Which language would you have preferred the guidebook to be written in? (Tick box/Comment)

HINDI	
MARATHI	
TAMIL	
GUJRATI	
OTHER	

6. Do you ever use the guidebook? (Tick box and add any comments if any)

NEVER	
RARELY	
SOMETIMES	
OFTEN	

SECTION E:

1. Did you prefer the group workshop (with option of home visits) or would you have preferred individual attention? (Tick box and add comments if any)

GROUP	
INDIVIDUAL	
NO PREFERANCE	

SECTION F:

1. What kind of nutrition programme would you prefer for your disabled child? (Tick box)

WORKSHOPS	
DAILY MEAL GIVEN	
VITAMIN /MINERAL TABLET COURSE	
HOME VISITS BY CHW	
MORE ADVICE BY DOCTORS	
OTHER	

THANK YOU FOR YOUR TIME.

Appendix 10: Transcript of Final Field Team Focus Group

Final Field Team Focus Group

Background:

The people who worked closely with the carers during the data collection period include: V. Jadhau (Community Health Worker (CHW) and field assistant in Phase II of data collection), G. Sayed, R. Shaikh, S. Kamble (Karuna Sadan Centre/ NGO), Sureka, Monika, Jyoti, Nirmala, Kalpita, Rewati, Maya, Sandhya, Sarita, Ranjani, Parwati (some work as pre-school teachers in the Spastics Society's Ugam project, others as CHW). All of these women had attended at least one project workshop. In addition the following ladies also attended the workshop: 1 ICDS teacher and helper (Anganwadi No.5, Kumbarwade Nagar, Dharavi) and 2 CHWs working in the Urban Health Centre (UHC) of Dharavi. All of these women live and work in Dharavi.

The women were invited to participate in a final project focus group to discuss both their opinions on the workshop and more generally on nutritional needs of disabled children in their community.

The focus group was held on 17th of April 2000 (during lunch time- the most suitable time for the working women). This was at the end of the project. A. Yousafzai conducted the focus group in Hindi. The focus group lasted 35minutes. It was held in the grounds of the UHC. Six women attended. Tea and lunch was served. Unfortunately the tape recorder borrowed from the UHC failed to operate. A. Yousafzai made notes on the discussion; (the first question is partly from memory, as it was not immediately noticed the recording was not happening).

Key Questions:

1. Do you feel the workshops were effective in passing on information regarding nutrition and feeding of disabled children to carers in the community?
2. Do you feel a "disability component" should be added in the training of CHWs, (particularly with regards to feeding)?
3. What kind of sustainable nutrition programme for disabled children is needed in Dharavi?

4. What do you feel the priority needs are for disabled children and their cares?

Focus Group:

1. Do you feel the workshops were effective in passing on information regarding nutrition and feeding of disabled children to carers in the community?

- I feel the main messages were conveyed and some of the information was applicable for all children. For example, informing mothers about free de-worming treatments. Many people here are unaware they have the right to access some treatments for free or just do not feel they can go to Sion hospital and ask.
- The guidebook was useful for us (*the community workers*) aswell as the mothers. It was simple and clear. The pictures are reminders of some of the things discussed in the workshop to help disabled children. It would be useful to have had one workshop just for community workers as we see these mothers all the time and can be in a better position to help them. It can make us more confident in feeding disabled children with serious problems where we may worry about them choking.
- I felt that many mothers came, but some of the mothers of more severely disabled children did not attend. The messages given in the workshop would have been really useful for these mothers. It maybe that they were working or with older disabled children they could not carry them to the meeting or find someone to look after the child at home.
- The information was given in a clear way. We can remember what was said. It was also useful to allow the mothers to discuss the issues and talk about good and bad experiences. We can all learn from each other. It was also useful to have offered home visits. That way, you do not focus on the questions and problems of one mother; otherwise the other mothers would have lost interest.
- The groups were a good size. The messages did come across clearly and the information was realistic. I hope the mothers practice what they learnt.

2. Do you feel a “disability component” should be added in the training of CHWs, (particularly with regards to feeding)?

- CHWs are poorly paid and these days we only receive a little training. Community Health Volunteer Workers (*CHVWs*) assist us and receive some training also. We used to get updates and training from social workers on a weekly basis. In the past few years that has cut down. There is little time and we usually receive new training only when a new project is to start. If a project on disability was to run then only we would be trained.
- New skills are useful. After all, we see the mothers more than the doctors. We also can identify the disabled children in the community and know which ones need help. The mothers ask us for help. Whether it is arranging therapy, visiting hospitals we are there for them. We can pass on more information clearly to the doctor than the mother sometimes. We are the ones most likely to help mother with problems like feeding. Mothers are more comfortable with us than the people at the hospital.
- It is always good to have more knowledge as a CHW. We see all the problems the mother is having, e.g. like when the child is not eating, and can help. However, who will teach all the CHWs these skills. The workshops were useful, but we need more such things for other workers.
- It is a good idea for us to know correct ways to solve feeding problems. These problems can be solved in the home with our help. The child and mother are happy. More workshops on topics like this would be useful.
- Yes, it would be useful to have training on disability and feeding. We will have to wait for a new programme in the area, which covers this topic. We learnt a little from this project which is helpful.

3. What kind of sustainable nutrition programme for disabled children is needed in Dharavi?

- The programme should be initiated by the government at the policy level for sustainability. The government can work with the NGOs as we more knowledge about the community.
- Nutrition programmes exist here. Disabled children do come to these and other programmes (e.g. Polio camps). We just need to make sure we have enough knowledge and skills to help the disabled children with real feeding problems.

- First, the mother needs to be more aware of disability. She needs to know her child has right to therapy, they should know the value of therapy, and she (*the mother*) needs to know where she can take the child. At the hospital he (*the child*) needs to be seen by doctors just like all the other children. How else will the disabled child have access to vitamin tablets or iron supplements? Improving awareness is very important. That should be the main disability programme. The CHWs play an important role here.
- Visiting each disabled child regularly is not possible. CHWs are very busy. We can teach the mother things about feeding on a couple of visits and monitor the child later in the same way the rest of the community children. Just from time to time or when the family draws our attention to a problem.
- A good programme needs good training and awareness. It also needs money to run for a long time.
- We need to fix the problems with our nutrition programmes so they work and reach all our children. We need to then include an extra part to the programme for the particular problems of disabled children.
- Shalom Church (*CORPs NGO- Sweden*) gives food to disabled children. They are mainly deaf.

4. What do you feel the priority needs are for disabled children and their cares?

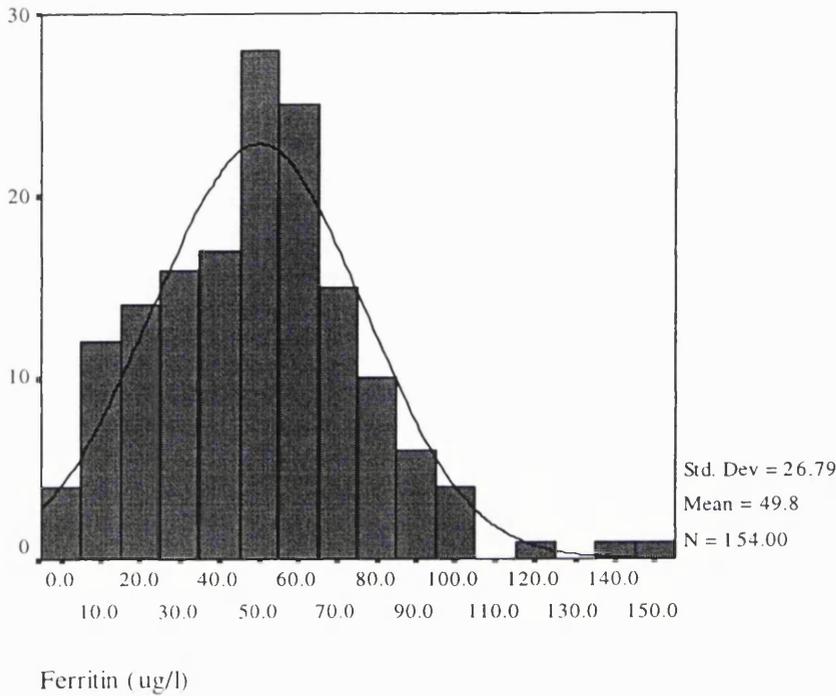
- I think the first thing is awareness of disability.
- Basic skills are lacking. Like we saw in the project with children being fed badly. We need to make mums aware. Even the fathers.
- Therapy and schooling are also important for the future of the child.
- We should give as much help as possible.

Thank you.

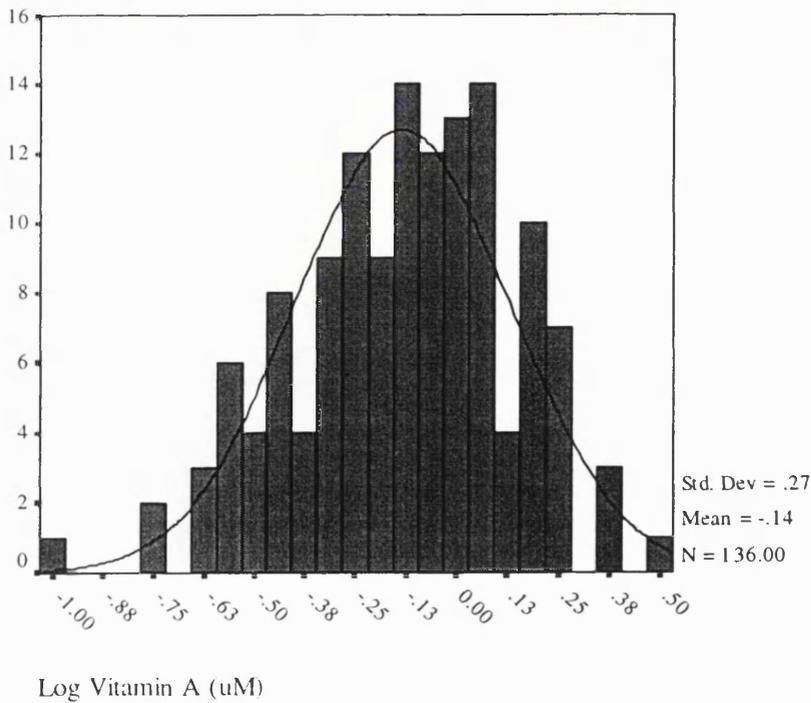
Appendix 11: Supplementary Micronutrient Data

Histograms to summarise the distribution data for the total study subjects for ferritin ($\mu\text{g/l}$), vitamin A (μM), vitamin D (nM), ACT (g/l) and CRP ($\mu\text{g/l}$).

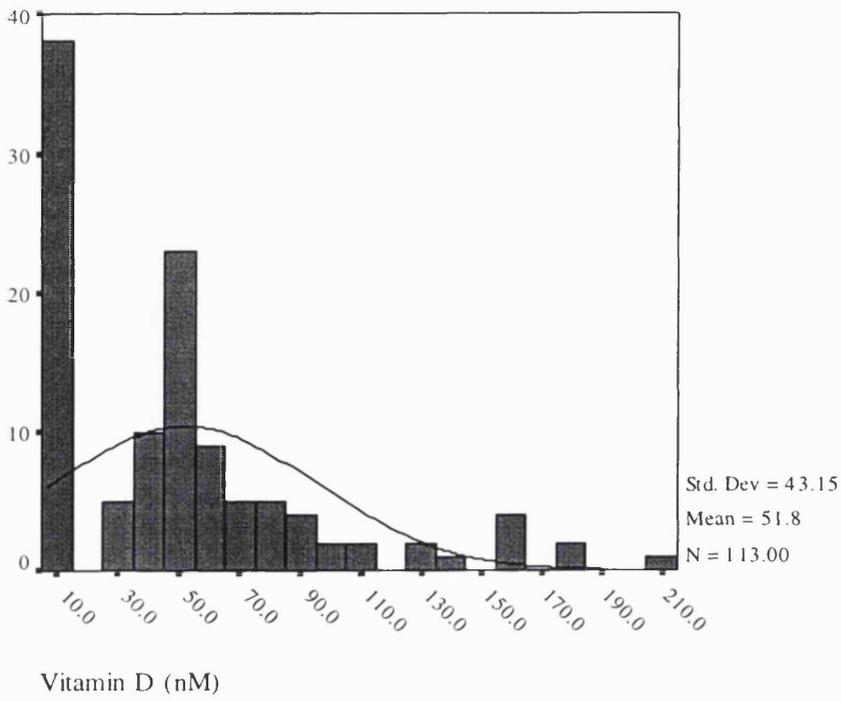
1. Distribution of ferritin ($\mu\text{g/l}$) results for all subjects.



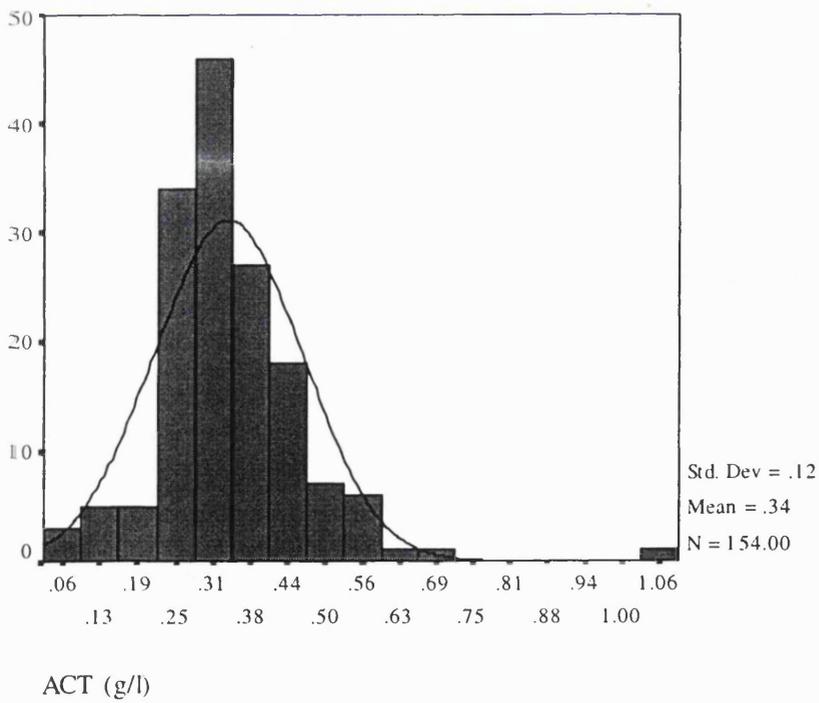
2. Distribution of Vitamin A (μM) results for all subjects.



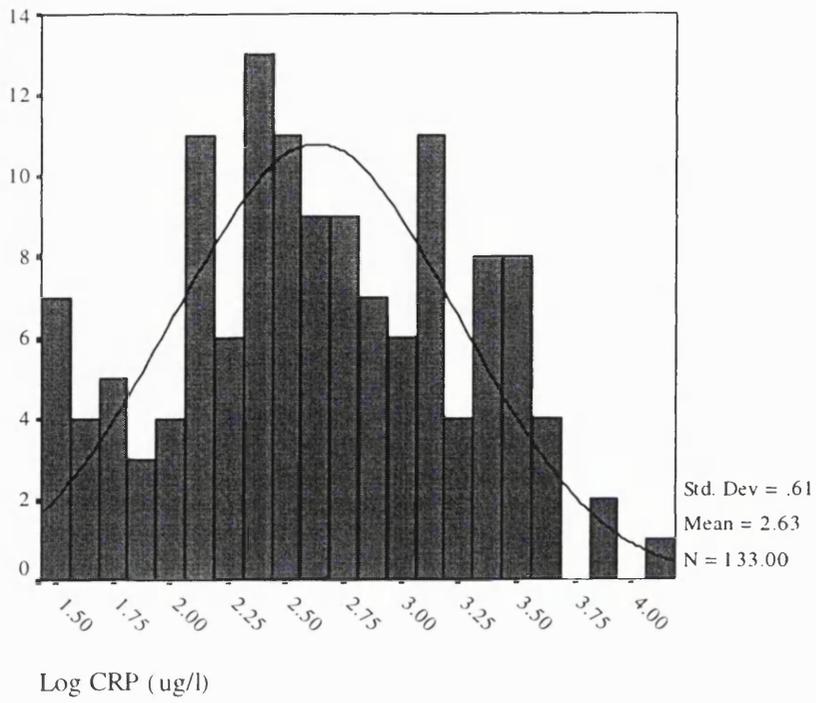
3. Distribution of Vitamin D (nM) for all subjects.



4. Distribution of ACT (g/l) results for all subjects.



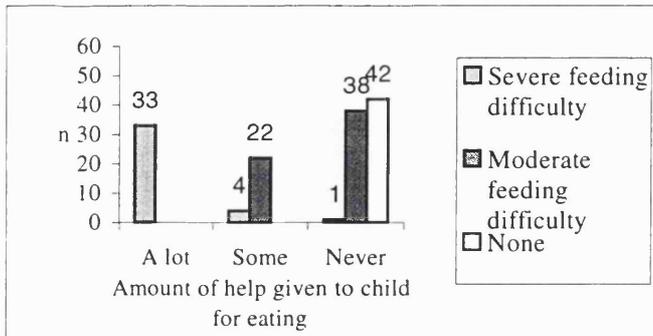
5. Distribution of CRP ($\mu\text{g/l}$) results for all subjects.



Appendix 12: Supplementary Data on Feeding Practices and Behaviours

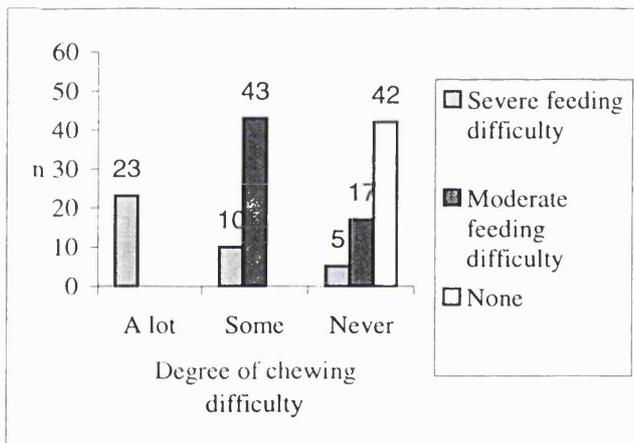
Figures to demonstrate feeding patterns by level of feeding difficulty of a child with disabilities (n=140).

1. A bar chart to show the number of children that require help with feeding:



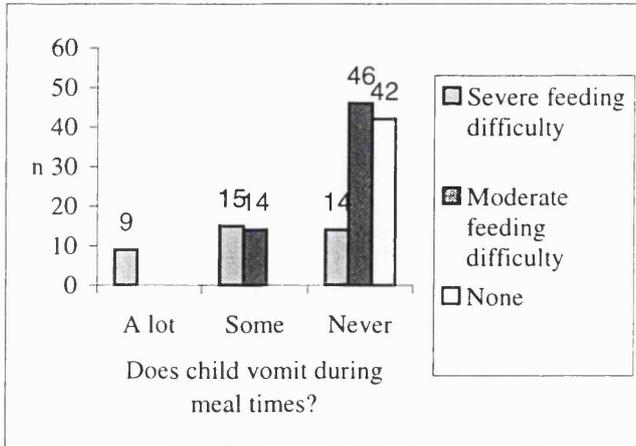
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

2. A bar chart to show the number of children that experience difficulties with chewing:



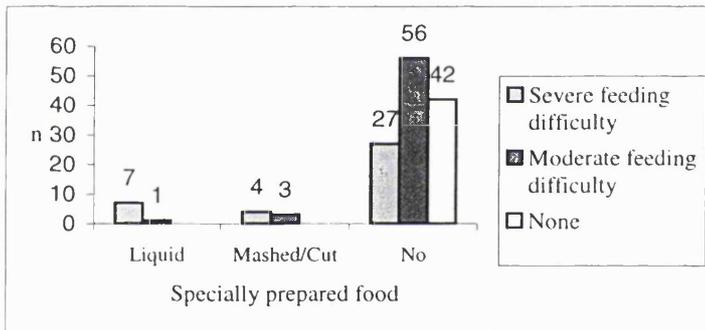
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

3. A bar chart to show the number of children that experience some degree of vomiting during meals:



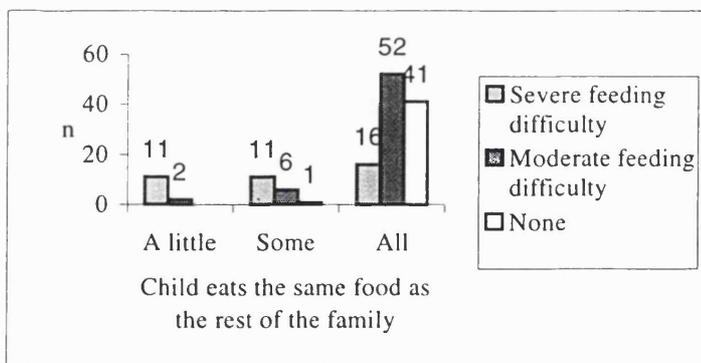
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

4. A bar chart to show the number of children that eat specially prepared food:



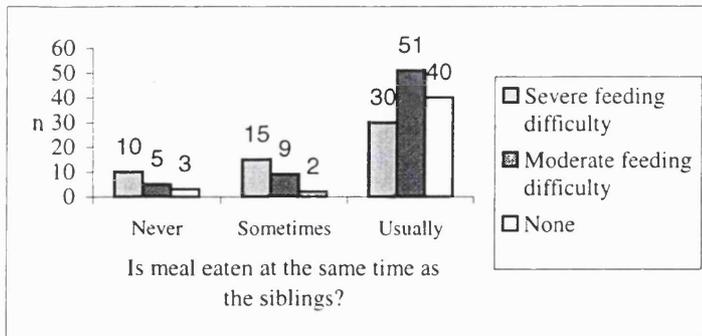
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

5. A bar chart to show the number of children that eat the same food as the rest of the family:



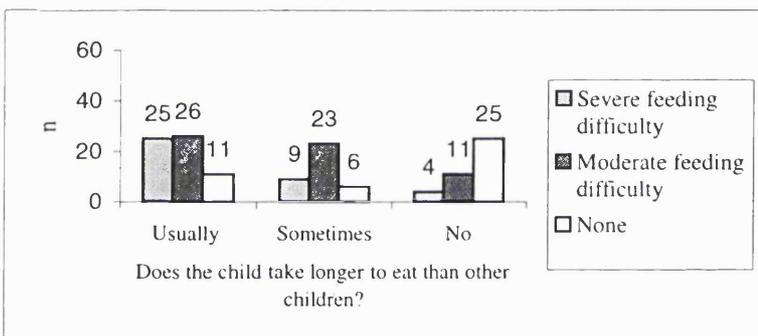
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

6. A bar chart to show the number of children that have meals at the same time as the other siblings:



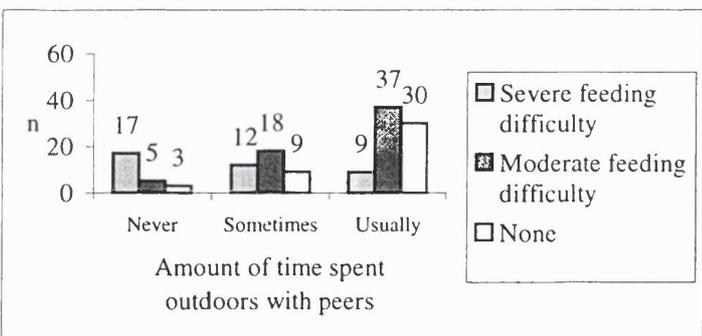
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

7. A bar chart to show the number of children that take longer to eat than other children of a similar age:



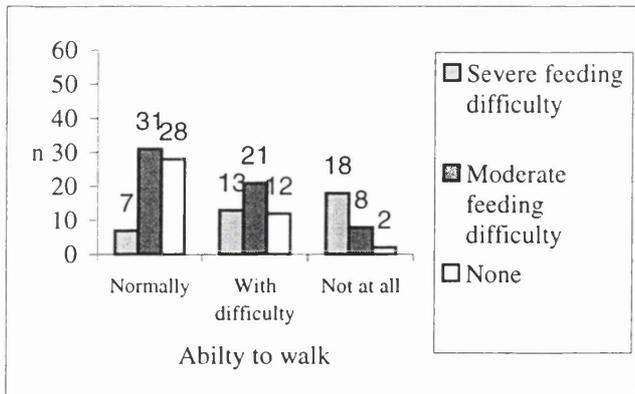
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

8. A bar chart to show the number of children that go out to play with peers:



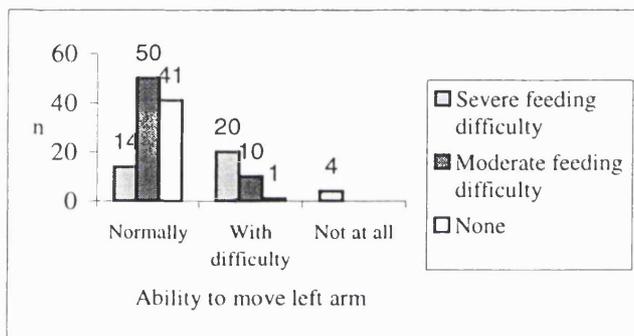
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

9. A bar chart to show the number of children that require assistance with walking:



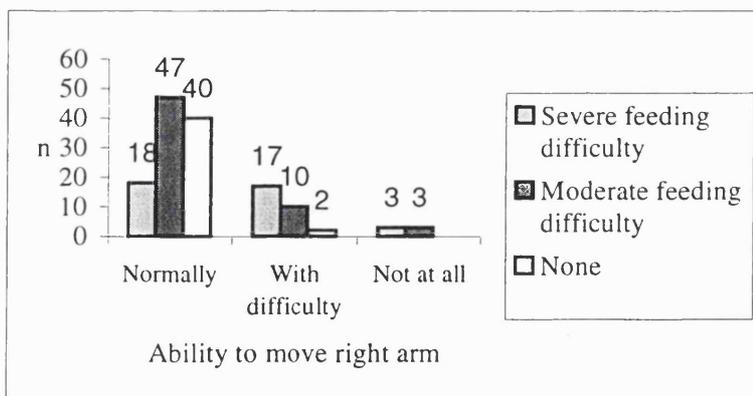
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=42.

10. A bar chart to show the number of children that have movement difficulty in the left arm:



Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=4

11. A bar chart to show the number of children that have movement difficulty in the right arm:



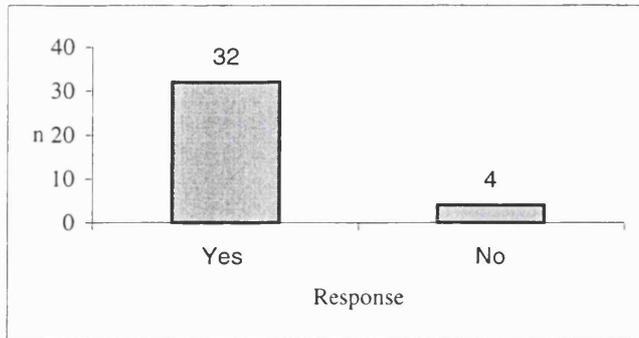
Note: Severe feeding difficulties, n=38; Moderate feeding difficulties, n=60; No feeding difficulties, n=4

Appendix 13: Supplementary Post-Workshop Data and Photographs

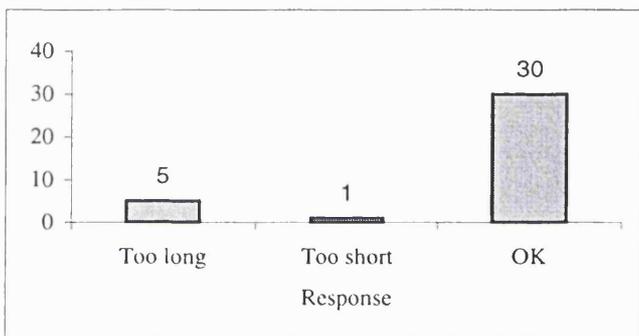
- Data
- Photographs from workshop.

Figures to illustrate carer (n=36) responses about the workshop and manual.

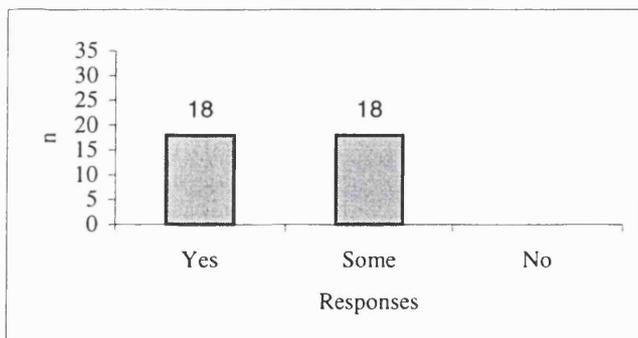
1. Were the workshops held at a suitable time?



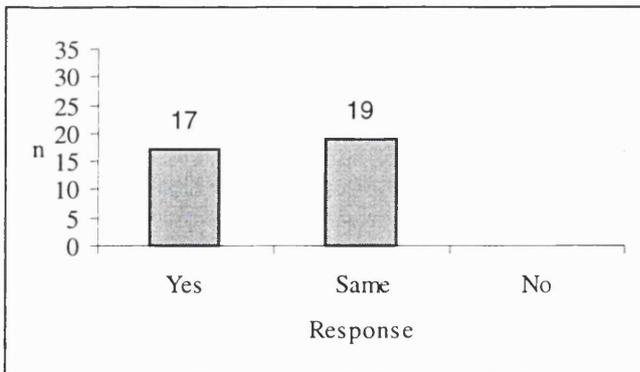
2. Was the duration time of the workshops suitable?



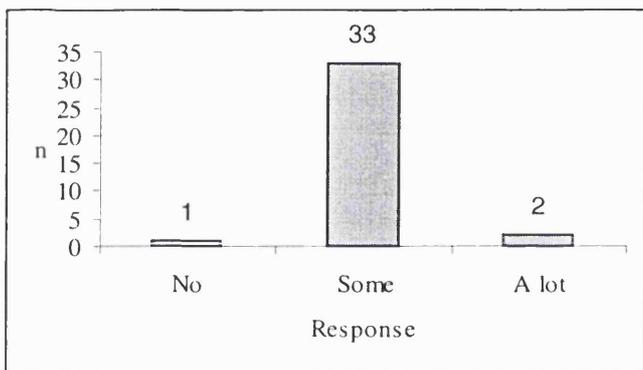
3. Do you feel the advice given was applicable at home?



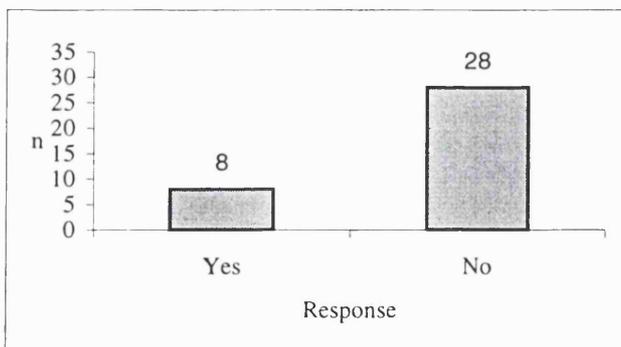
4. Do you feel more comfortable feeding your child since the workshops?



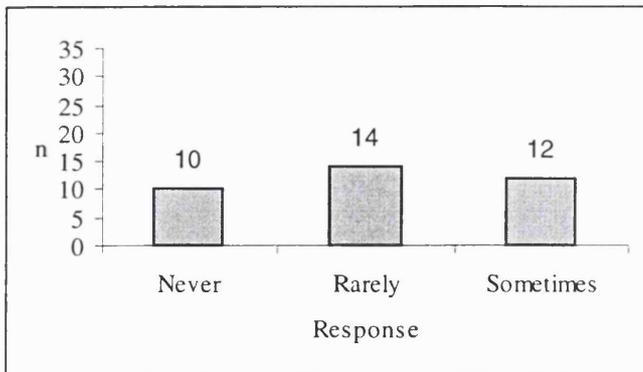
5. Do you feel your child has benefited from you attending the workshops?



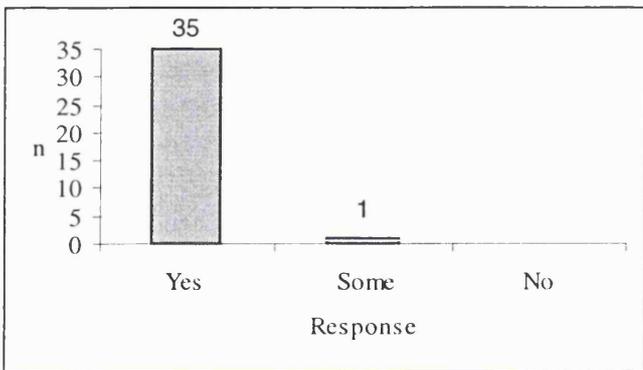
6. Do you feel further information should have been included in the workshops?



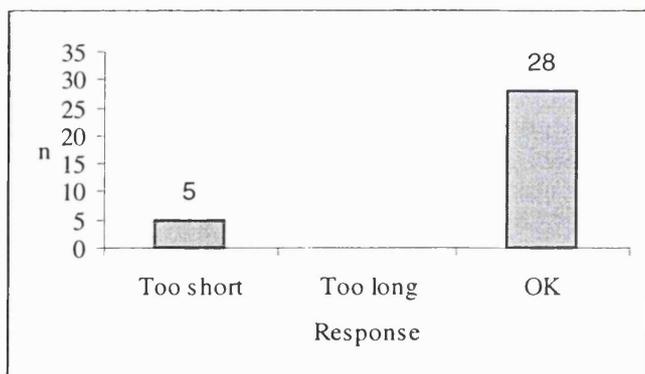
7. Do you use the workshop manual?



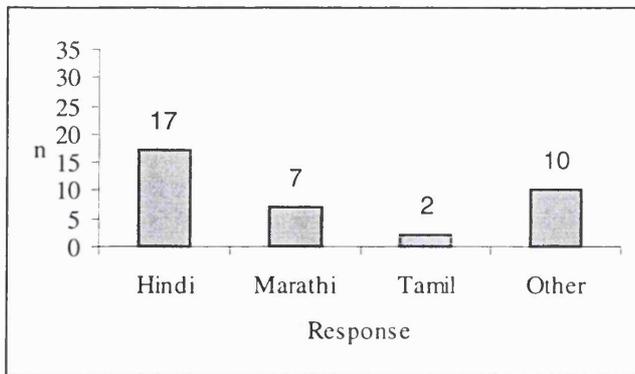
8. Did you find the manual easy to follow?



9. Do you feel the manual is a suitable length?



10. What is the preferred language for the manual?



Photographs of Workshops

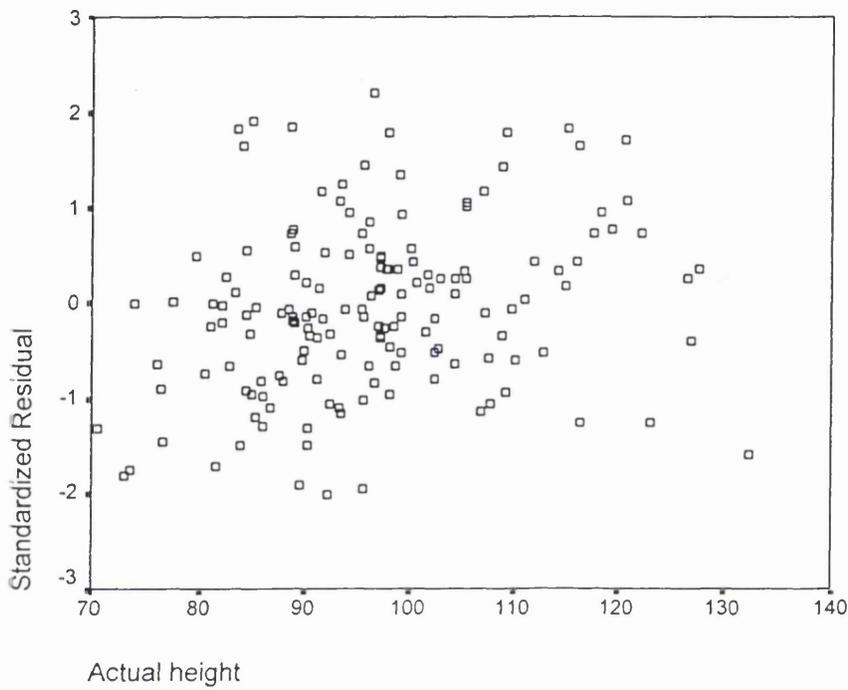
1. Participants sharing experiences in workshop 1.
2. Cooking demonstration with participants in workshop 2.



Appendix 14: Residual Plots for Height Prediction Models.

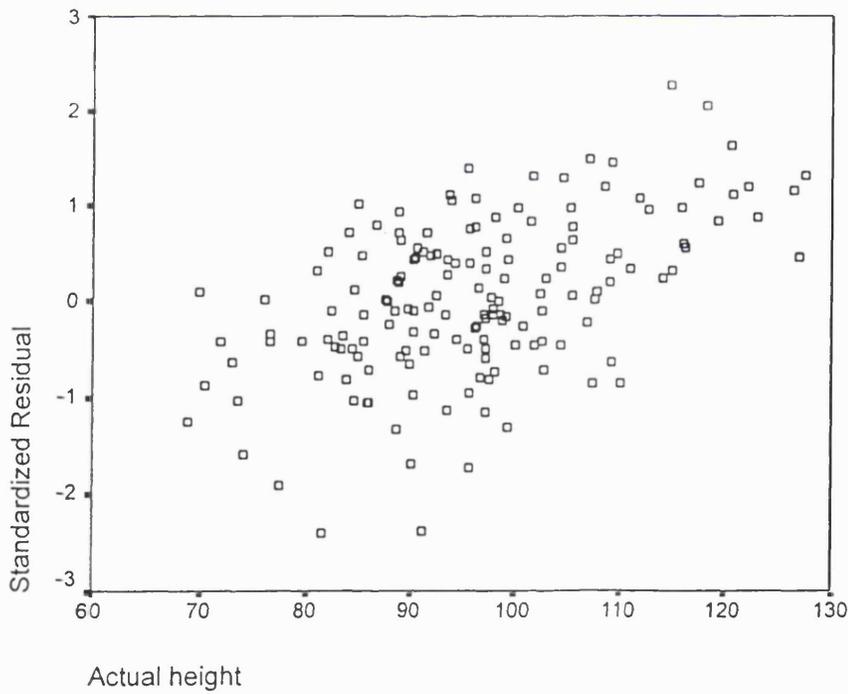
Residual plots for height prediction models on neighbour children:

1. Height prediction from armspan:



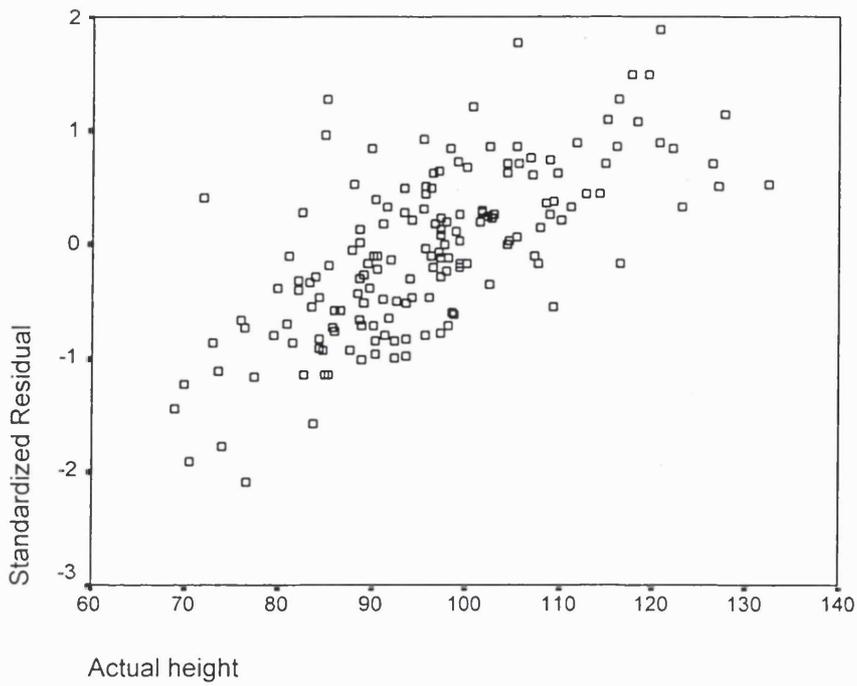
Note: $r=0.966$, $P<0.001$, $n=158$.

2. Height prediction from tibial length:



Note: $r=0.851$, $P<0.001$, $n=161$

3. Height prediction from arm length:



Note: $r=0.903$, $P<0.001$, $n=162$

**The Nutritional Status of Disabled Children Living in Dharavi, an Indian Urban Slum
in Mumbai.**

(Supplement)

Aisha Khizar Yousafzai.

A thesis submitted for the degree of Doctor of Philosophy
University of London

May 2001

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London,
WC1N 1EH.

अपंग बच्चों को खिलाने की
प्रक्रिया !



धारावी में अपंगों की देखभाल करने
वालों के लिए जानकारी !

CENTRE FOR INTERNATIONAL CHILD HEALTH

SPASTICS SOCIETY OF INDIA.

अनुक्रम

परिचय !

बैठाने का तरीका !

स्वास्थ्य की जानकारी !

खिलाने की तकलीफों की व्यवस्था !

पिने की तकलीफों का व्यवस्था !

अपने आप खाना !

अंधे बच्चों की जानकारी !

दाता का देखभाल !

सामान्य जानकारी !

१. परिचय

• हमें खाने की अच्छे आदतें क्यों सीखनी चाहिए !

१. अच्छे सेहत के लिए जरूरत है !

२. अच्छे खाने के तरीके सीखने से दूसरे !

चीजों में भी लाभदायक

[जैसे] बोलना, बढने में आसानी

• अंपंग बच्चों में खाने और पीने की तकलीफों बहुत से कारण है !

• यह किताब आप को खाने और पीने की तकलीफों की जानकारी देगी !

• अंपंग बच्चों को भी वही भोजन की जरूरत है जो आम बच्चों खाते है !

• अंपंग बच्चों का स्वास्थ्य अच्छा रखने के लिए और बिमार न होने के लिए उन्हें खाने के लिए प्रोत्साहित करना चाहिए .

• कमजोर बच्चों .

— उनका शरीर ठीक से बढ़ता नहीं
और वजन कम रहता है !

— खेलते समय और पढ़ाई के समय
ताकत नहीं रहती !

— बार - बार बीमार हो जाते हैं !

• जो बच्चा अच्छा खाना खाता है,
उसकी अच्छी सैहत रहती है !

२. बैठने का तरीका .

खाना खाने समय बैठने के अच्छे तरीके



यह तरीका
खिलाने और
पिलाने समय
उपयुक्त है !

बच्चे की गोदी में बैठकर अपना हाथ से
उसके कंधों को सहारा दें ताकि उसका
सर ठीक से रहे !



• जो बच्चा अपने आप
से बैठता है उसको
दीवार का सहारा दें ।

• जो बच्चा गद्दिन समानत
है उसको इस तरीके से
खिलायें !

• बच्चे को लिटाकर और उसका
सिर पीछे रहते वक़्त खाना कभी
न खिलायें !

• बच्चे को लेटाकर खाने खिलाये
तो बच्चे को दियकी लम्बा सकती
है जिससे उसको सांस लेने में
तकलीफ़ हो सकती है !

३. स्वास्थ्य की जानकारी

जीवनत्व/ स्वनिज पदार्थ	काम	रवाना
१. A सत्व	आँखों के लिए ज्यादा इन्फेक्शन होने से बचाता है	गाजर, टमाटर हरा बटाना सूखा अकसूट!
२. D सत्व	दड़ियों के लिए दाँतों के लिए जरूरी है।	'धूप' मटछी!
३. C सत्व	इन्फेक्शन होने से बचाता है।	हरि पत्तवाली सब्जी, टमाटर, बटाटा!
ओह सत्व	खून बढ़ने के लिए और मसल (पेशी)	दाल और हरि पत्तवाली सब्जी!

- खाना बनाने से पहले हाथ धोए और बर्तन भी धोयें।
- सब्जी काटने से पहले धोए फिर काटे - क्यों के विटामिन्स नष्ट न हो
- सांजियाँ उबालते समय ढक्कन कर रखें ताकि विटामिन्स नष्ट न हो
- चपाती व दूसरे खाने में ज्यादा हरी सांजियाँ वापरें।

• ध्यान दें :- धूप से विटामिन D मिलता है सब बच्चों को विटामिन की जरूरत है सब बच्चे धूप में १०-१५ मिनट गुजारना जरूरी है अंपंग बच्चे जो चलते नहीं उन्हें भी १०-१५ मिनट धूप में रखना जरूरी है।

• विशेष खाना :- जो बच्चों को
चवान और निगलने में तकलीफ
है उन्हें पानी के पदार्थ से
ज्यादा सरल पदार्थ खिलाने की
कोशिश करनी चाहिए!

सूजी और दूध,
पाव और दूध!

बटाटा को मसल कर दे सकते हैं,
केल को मसल कर दे सकते हैं,
खिचड़ी दे सकते हैं!

रोज थोड़ा थोड़ा कर के उनको यह
खाना खाने की आदत डालें!

• अगर बच्चा बिमार हो तो भी उसे खाने के लिए प्रोत्साहित करें बच्चा मना करे तो भी उसे फिर से कोशिश करें. क्यों के बिमार बच्चे को ठीक होने के लिए खाना जरूरी है !

• पूरे परिवार के साथ खाये सेहत के लिए पौष्टिक आधार जरूरी है ! [माँ, बाप और भाई बहन!]

• जन्म नारक औपच्य साल में दो बार दें यह औपच्य B. M. C अस्पताल में मुफ्त है !
नाम : मैक्स !

४. रिक्ताने की तकलीफों की स्थिति .

- भावुकता .



- जबड़ा कंट्रोल .



बच्चे के पास
बैठ !



बच्चे के सामने
बैठ !

• चम्मच और हाथ से खिलाने की विधि

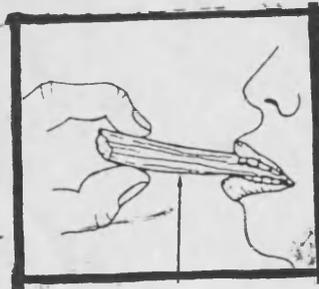


ठीक तरीका ! ~~गलत तरीका !~~ ~~गलत तरीका~~



• जबान संभालना .

← अच्छा खिलाने का तरीका !

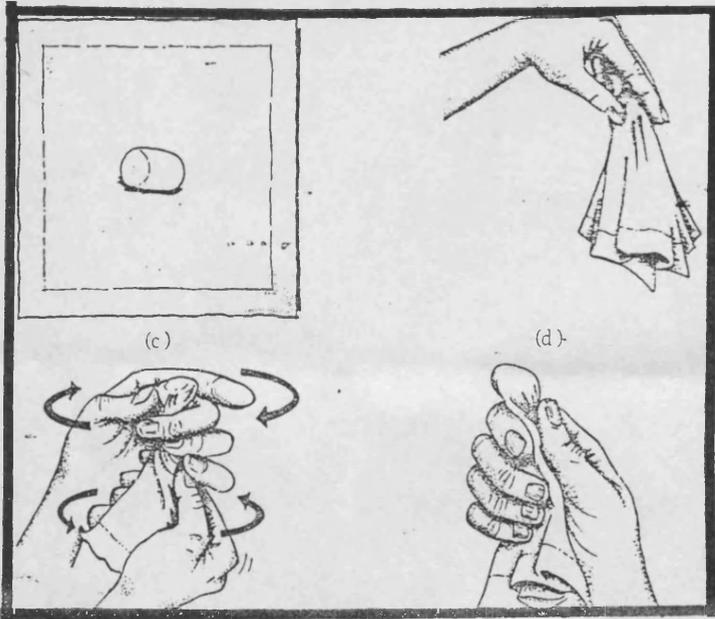


• काटना .

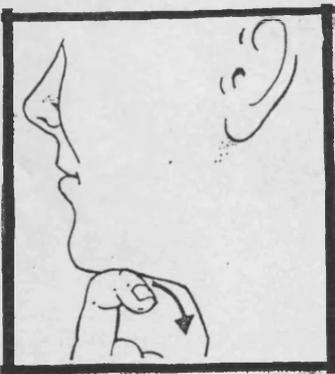
तरल पदार्थ से शुरूवात करें।
खाना दातों के बीच रखें
फिर मुँह धीरे से बंद करें।
सर को पीछे की तरफ
मत जाने दें !



• चबाना .
 बच्चे को चबाने के
 लिए मदद करें
 खाना बच्चे के मुँह में
 किनारे पर दें !

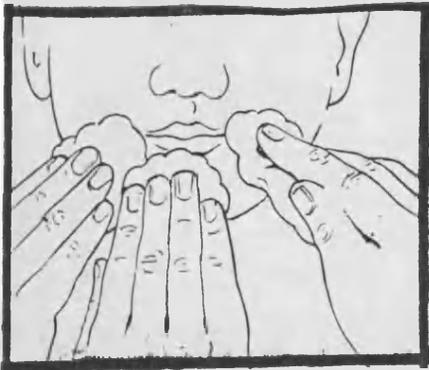


बच्चे को
 चबाना सिखाने
 के तरीके !



• निंगलना .
 गाले पर हल्की
 मालिश दें !

• थूँक बाहर निकालना .



मुँह पीछे

सर बराबर रखें !

सर पीछे की तरफ मत जाने दें !



बच्चे को होठ बंद रखने की आदत डालें !

बच्चे को अपना मुँह खुद पीछने की आदत डालें !



• टिचकी (CHOKING!)

अगर बच्चे को टिचकी लगे तो बच्चे का सर और कंधा आगे की तरफ करें !

टिचकी के समय बच्ये को पठि और
सर मत तपतपायेँ और मुँह से खान
निकाल लै!

मुँह पर खाना फँसा हुआ है या नहीं
यह जाँच करेँ और उसे निकाल लै!

• उल्टी

- बच्ये को भूख नहीं है तो जबदस्ती
मत खिलायेँ!

- बाद में खाना खाने को उत्साहित
करेँ!

- अच्छी तरह से चबाकर खाने को
सिखायेँ!

- थोड़ा-थोड़ा खाना कर के खिलायेँ

"खाने के बाद बच्ये के मुँह में कोई
खाना बचा है यह जानकारी कर लै
कुल्ला करायेँ या पानी पिलायेँ!"

५. पीने की तकलीफों का व्यवस्था.



आरुछा वीरुन का
नशीका !



आरुचन वीरुन का व्यवस्था।
पानी पीने वचन हींठ
दवान का सिरवायें ।



आरुचन की दान के जमास
न कादने दें ।

६. अपने आप खाने की आदत.
यह भविष्य के लिए जरूरी है.



- आराम से बैठें, जरूरत हो तो सघरा दें, हर बार थोड़ा मदद करने की कोशिश करें बच्चा अटछा करे तो उसे वाह वाह करें बच्चे को अपना हाथ इस्तमाल करने दें दाया हो या बाया !
- चपाती छोटे छोटे टुकड़े कर के दें.
- बच्चे का हाथ साफ रखें बच्चे के बाल पीछे रखें ताकि बच्चा खाना आसानी से देखने को मदद हो !

७. अंधे बच्चों की जानकारी.



• बच्चे के हाथ की मदद से खाना की प्लेट को छू कर दिखाये!



• हर वक़्त बच्चे को खुद खाने की कोशिश करने दें!

८. दाँतो का देखभाल .



- दाँत साफ रखना जरूरी है !
अगर हम बच्चे को ज्यादा मीठा खाने दे तो बच्चे के दाँत खराब हो सकते हैं और अगर दाँत साफ न रहे तो मीठा दाँतो को खराब कर देगा !
- बच्चे को लाल टपकाने से रोकने की आदत डालें !

९. सामान्य जानकारी

- कुकींग वर्कशाप
2 माला, नागरी भरोग्य केंद्र
60 फुट रोड, धारावी - १७.
- थेअरपी सायन हॉस्पिटल, वीएमसी, मुंबई.
- स्कूल / थेअरपी
करुणा सदन शाखा (एस.एस.आय.)
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धारावी - १७.
- उगम अंगणवाडी (एसएसआय).
 - प्रेरणा.
 - राजीव & गांधी नगर धारावी - १७
 - आशा
राजीव गांधी नगर धारावी - १७
 - मैत्री
आंबेडकर नगर, धारावी
 - शांती
कालाभरणी, नाईडनगर धारावी.
 - ज्योत्स
प्रेमनगर धारावी.

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ILLUSTRATIONS FROM:

1. "FEEDING FOR THE CHILD WITH CEREBRAL PALSY" - INDIAN INSTITUTE OF CEREBRAL PALSY
2. "PROMOTING THE DEVELOPMENT OF YOUNG CHILDREN WITH CEREBRAL PALSY - A GUIDE FOR MID-LEVEL REHABILITATION WORKERS" - W. H. O.
3. "HOW TO RAISE A BLIND CHILD." - D. FICHTNER.
4. "DISABLED VILLAGE CHILDREN." - D. WERNER.
5. "THE PRACTICAL MANAGEMENT OF EATING AND DRINKING DIFFICULTIES" - A. WINGSTOCK.