Urban Community Based Rehabilitation Project
India
FINAL REPORT

- changes from National Workshop document indicated by underlining
- I have not changed the page numbers in the index
- ** asterisks denote the start of changes and are search flags. They will all be removed automatically at the end.

inputs and discussion needed:

1. statement about lack of data on low income communities - eg for housing, % coverage of primary education, 5 employment in slums etc. There is no data available that puts it in percentages - the only stuff we have found is for whole cities and is in absolute numbers with no indication of the numbers not.
2. Define learning difficulty (and compare with MR and learning disability for the audience)
3. age distribution
4. efficiency of NGOs

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Child In Need Institute (CINI) Calcutta, South Bank University,
and the Institute of Child Health, London.

Project for the Government of India,
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i. EXECUTIVE SUMMARY

1. Background

With rapid urbanisation and the growth of urban poor communities, the Indian Ministry of Welfare is seeking an appropriate model of service provision for persons with disabilities in urban areas. Any model should take into consideration both the special characteristics of poor urban communities, and the experience and performance of urban services. The Urban Community Based Rehabilitation (UCBR) Project was set up to do this.

2. Aims

1) to conduct community studies in low income communities in Bangalore, Calcutta and Visakhapatnam to explore: i) the expressed needs and experiences of persons with disabilities and their families in low income communities and ii) experiences of existing services in relation to these needs.

2) to evaluate eight approaches to service provision in the three cities in relation to these needs.

3. Methods

587 persons with disabilities and their families from randomly selected slums in three cities, Visakhapatnam, Bangalore and Calcutta, were interviewed by questionnaire covering socio-economic, socio-cultural information, community life, service use, plus qualitative discussion of needs. 22 focus group discussions (FGDs) covering 144 persons with disabilities and family members were held to discuss experiences and needs. Eight service approaches, including government and NGO, centre and community based were studied. A questionnaire was used with a random sample of 492 service users covering socio-economic, socio-cultural information and service use. 40 FGDs explored with 240 people, socio-economic, socio-cultural information, and experiences of service. Individual and group interviews were held with staff members about staff attitudes, and service costs. For a range of 6 impairment groups, the service use of a total of 60 persons with disabilities was both observed and followed up afterwards, in order to measure the quality of medical rehabilitation.

4. Results and draft recommendations

4.1 Disability and poverty must be addressed together

Whatever the situation, the additional costs of disability make families poorer. The needs of persons with disabilities should be included in mainstream urban poverty eradication programmes. The principle of inclusion means that persons with disabilities and non-disabled people have equal opportunities to share in mainstream activities. The barriers that prevent such inclusion, which include economic, structural, environmental and attitudinal, should be identified, analysed, and removed.

4.2 Representation of poor persons with disabilities must be a foundation of their inclusion in mainstream development.

This study found that the priority needs expressed by urban poor persons with disabilities and their families are for income and education, priorities in common with poor non-disabled people. 59% of men and 79% of women with disabilities were unemployed. Policy and practice should enable persons with disabilities and their families from low income areas to express their own needs in the development process.

The study found that women with disabilities were significantly less likely to attend school or do paid work than men, and were perceived to be exposed to greater risks. Women and girls took on considerable additional work in caring for persons with disabilities, in isolation, and without support. Policy must ensure the equal representation of poor urban women with disabilities and their female care givers to express their specific needs through a community based approach.

This study found that a barrier to persons with disabilities' inclusion in structures is the excluding attitude of staff in government departments, community development, public transport, hospitals, schools, NGOs, urban development, and donors. Awareness and action training on disability and poverty, centred around the social model of disability and barriers approach, and lead by persons with disabilities, should be compulsory for all central and state government staff, municipalities, NGOs, and donors. Persons with disabilities should be included into the network of community development services, from the relevant Ministries' actions to community level structures.

Most importantly, all urban local bodies such as municipalities, corporations, and community development societies should ensure adequate resource allocation for the implementation of inclusion of persons with disabilities in all their programmes, including support for the informal sector, such as self employment schemes and allocation of space for small and medium sized enterprises. Inclusion can be enforced through budget allocation, much as all development budgets and activities must include the needs of women. Government and donors should adopt inclusion as a pre-requisite to resource allocation.

4.3 Support the family and community

The study found the greatest support for persons with disabilities came from their own families, and their immediate communities, and not from government or NGOs. The greatest needs expressed by persons with disabilities and their families were economic. Support, including money, should be given to family and community based income generation groups complemented by group managed day care, and emotional and social support. Provision of loans for persons with disabilities already exist in India, but in the three community studies only one of 587 persons with disabilities interviewed had secured a loan. Policy and practice should treat persons with disabilities as a priority group in micro- finance schemes. Loans should be available to care givers when persons with disabilities cannot work themselves on account of their disability.

The study found that five times as many children with disabilities were served by local mainstream schools as by special schools. Mainstream schools should be supported to include the needs of all children, including children with disabilities, within their catchment area by changing national and state teacher training curricula, the physical environment of schools, learning materials, and providing disability awareness training for all staff, non-disabled children and their families.

4.4 Centre based services do not meet the needs of urban poor persons with disabilities

This study found that centre based services which focused primarily on medical rehabilitation and segregated education do not include or meet the needs of poor urban persons with disabilities. In one city in which 38% of the community study sample lived in kutcha (poor) houses, only 4% of users of centres came from this socio-economic group. Thus centre based service provision reinforces inequity. Poor people are unable to access centre-based services because of barriers related to the cost and time of travel. These become increasingly important when non-mobile children get older and heavier.

Centre based services focus on medical needs which are not the priorities of poor people. Medical rehabilitation has a limited role in meeting the needs of the urban poor. It is inappropriate for centre based medical services to manage community based services.

Accepting that all services are inadequate, financial and skill resources should be directed towards community based structures that demonstrate that they effectively reach poor people. No additional resources should be put into centre-based referral services unless they meet the criteria of equity (priority coverage of those most in need) and quality, and support community based approaches. No additional resources should be put into any other centre based services.

4.5 NGO and government roles

This study did not find evidence to support that NGOs are more successful than government at reaching poor people at community level. The study found that the most important determinant in reaching the urban poor was a community-based approach as part of general community development. This was true for both government and NGO services. Allocation of resources for persons with disabilities should continue through the community development structures of both government and NGO sectors.

4.6 Monitoring and evaluation

This study found that coverage of urban poor persons with disabilities by service organisations is extremely limited. Less than 5% of persons with disabilities interviewed in the community studies had used NGO rehabilitation services. 88% had used government medical rehabilitation services, but the services were of poor quality and expressed medical needs were not met. Government and donors should make effectiveness in meeting the real needs of urban poor persons with disabilities a prerequisite of resource allocation.

The study found that government benefits have extremely limited coverage and are not equitably distributed. Significant barriers to access exist in government structures. Government should monitor the coverage of welfare provisions such as disability certificates and loans, and address institutional and attitudinal barriers to their distribution.

4.7 Towards a model of urban community based rehabilitation

It was anticipated that one of the approaches or a combination of the elements from different approaches, would emerge as a model for urban community based rehabilitation. This was not the case. However, the study found compelling evidence that suggests that certain characteristics would be appropriate in such a model. These are presented in the report and will be discussed at the national workshop.

ii. ACKNOWLEDGEMENTS

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Above all, we thank the persons with disabilities and their families in low income communities of Calcutta, Bangalore, and Visakhapatnam who were involved in the UCBR study. They shared their views and experiences on the understanding that policy and practice will better meet their needs.

iii. GLOSSARY

CBR	Community Based Rehabilitation
DRC	District Rehabilitation Centres
FGD	Focus Group Discussion
ICDS	Integrated Child Development Centres
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
ILO	International Labour Organisation
NRS	Nil Ratan Sarkar
OPD	Out Patients Department
PIED	Project Integrated Education for the Disabled
SIP	Slum Improvement Project
UBSP	Urban Basic Services Programme
UCBR	Urban Community Based Rehabilitation
UNESCO	United Nations Education Cultural and Scientific Organisation
VRC	Vocational Rehabilitation Training Centres
WHO	World Health Organisation

SECTION 1 INTRODUCTION

1.1 BACKGROUND

The Indian Ministry of Welfare (MOW) has developed a model for community based rehabilitation (CBR) in rural areas. With rapid urbanisation and the growth of urban poor communities, the MOW wished to investigate an appropriate model for urban areas, which takes into consideration both the special characteristics of poor urban communities, and the experience and performance of urban services. The MOW approached the then Overseas Development Administration (now the Department for International Development - DFID UK) for technical assistance. The collaborative project undertaken uses the complementary experiences and skills and of service providers in three cities; Calcutta, Bangalore and Visakhapatnam, together with an Indian Co-ordinating Agency (Child-in-Need Institute - CINI, Calcutta) and the UK's Institute of Child Health and South Bank University. The project involved an evaluation examining the activities, coverage, quality, cost, and ability to meet the expressed needs of persons with disabilities. These needs were investigated through community studies in the three cities. This document, including draft recommendations for urban policy, is the product of this process.

To our knowledge, this is the first study to measure needs and experiences from the perspective of persons with disabilities and their families in low income urban communities in India. Of the UCBR Project's findings, the joint Secretary, Ministry of Welfare, commented:

> "For the first time we have the perception of the poor disabled user".
>
> Ms Gouri Chatterjee, Joint Secretary,
> Ministry of Welfare, Government of India.
> New Delhi ,7th April 1998

1.2 BRIEF LITERATURE REVIEW

1.2.1 Prevalence

Prevalence studies in the field of disability are fraught with problems of definition, exclusions, inaccuracies, disillusionment of those surveyed, and are also expensive. Hence, the World Health Organisation (WHO) stated that every dollar spent on disability surveys and not on service was a dollar wasted (1984). Data already exists from national surveys of prevalence of persons with disabilities in India, carried out in 1981 and 1991. The 1981 survey (Ministry of Welfare, GOI, 1982) came up with an overall figure of 1.84% and the 1991 figure was 1.99% (Pandey and Advani, 1995). However, this figure is low since only three categories of disability were recognised; motor disorders, visual and communication difficulties. Mental illness, behaviour problems, intellectual difficulty (mental retardation), leprosy and epilepsy were not included. There was a higher prevalence of disability in rural compared with urban areas (20/1 000 to 16/1000), more males were identified than females and there was a higher prevalence in the over 60's. The definitions used in the WHO International Classification of Impairment, Disability and Handicap were not used but this classification is in process of revision into categories of impairment, activities and participation.

<u>* definition of disability</u>

Most local studies find higher prevalence rates. For example a study of ten Anganwadi centres in an ICDS urban project found a prevalence rate of 7.6/1000 (Mathur et al 1995). The prevalence rate of neurological disorders alone in a small study in urban Bangalore was 32.8/1,000 with a rate for epilepsy of 7,8/1,000 (Gourie-Devi et al, 1996).

1.2.2 Poverty

A higher prevalence of disability amongst poorer people is consistently found in international studies. For example, a Canadian study examines the close bond that fuses disability, low participation in employment, and poverty (Rioux and Crawford, 1990). In the UK, young, mainly physically disabled people perceived that poverty, disability and ethnic background isolated them from the wider community (Doyle et al, 1994). In South Africa disabled black miners' compensation payments were lower than poverty datum levels and were further eroded by inflation (Leger and Arkles, 1989). A study from the Republic of Ireland found a clear gradient in relation to socio-economic status in the overall prevalence of cerebral palsy, hemiplegia and diplegia associated with low birthweight (Dowding and Barry, 1990). Since the incidence of low birthweight is higher in poorer communities, it is probable that this differential would be the same or more marked in India. Studies based on USA census data show that highest rates of work disability occur in rural, female, elderly, less educated, African-American and below poverty level populations (Holzer et al, 1996). But it was also found that poor inner city African-Americans do not have adequate access to remedial programmes (Miller et al, 1996). More inclusive workplaces and an income system that is more rational and equitable is proposed to combat some of the inequalities of poverty (Rioux and Crawford, 1990).

There are a few important studies on socio-economic differences in urban areas in India in relation to disability. A study from Calcutta of 35,266 people showed that the prevalence rate was three times higher in the lowest income group than in the highest income group (Ghosh et al 1984). An important and careful study of the prevalence of serious disability in two neighbourhoods in a Southern India city showed that all types of disability were consistently more prevalent in the "lowest" socio-economic group. The prevalence of disability in the lowest socio-economic group was 17.2% compared with 8.4% with the "next-to lowest" socio-economic group. The study did not include "higher" socio-economic groups (Natale et al 1992).

1.2.3 Costs to the family

A detailed study in the UK showed that the costs of caring for mentally handicapped children were significant and diverse, potentially affecting the quality of life of all members of the family (Baldwin and Gerard, 1990). This study found not only that working mothers and fathers earned less than those in a control group, but also that the life span earning curve for all classes of families who had a disabled child was 'flat' whereas there was an upward curve for the control group. Although we have found no such detailed studies from India it is inconceivable that the effect would be less in India where social services cannot cushion such economic effects. In fact, a study from Chandigarh showed that families with children with disabilities perceived greater financial and other stresses when compared with the families of control children (Singhi et al, 1990).

1.2.4 Services for persons with disabilities

Few participatory evaluations of existing services investigate the demography of the population covered by those services in relation to the population most in need. Thus the essential question of the equitable distribution of services is not addressed. The obvious implications for health care reform are that there should be greater access to services for populations of greater need. Historically and in many current contexts, the opposite is true, thus exacerbating the observed differentials.

Where resources are limited it is acknowledged that people with disabilities in rural areas and in poor urban areas do not get adequate services. India has produced many descriptions of service approaches for persons with disabilities, including government hospitals, national institutes, NGOs, special schools, community programmes, and camps. However, very little is known about whether these services include the urban poor or meet their expressed needs. Despite a paucity of evidence of their effectiveness, these approaches continue. For example, Pandey and Advani (1995) report the limitations of the camp approach, concluding that "although this approach has been found to be handy in a situation where infrastructure is scarce, good quality and comprehensive services are not possible through this approach". Nevertheless this approach is still supported by government, NGOs and donors alike.

The Indian rural CBR scheme based on the rural District Rehabilitation Centres (DRCs) was evaluated in 1989. The scheme had considerable impact, although it is important to note that Pandey and Advani state that the programme was community located but not community based, and that urban areas were not included. The "level of satisfaction was low as the DRC scheme failed to fulfil the high expectations of providing comprehensive rehabilitation including economic rehabilitation which it had given rise to in the community" (Pandey and Advani 1995; p.129).

Recognising the poverty of whole communities, the concept of CBR developed so that a Joint Position paper (1994) of the International Labour Organisation (ILO), United Nations Education Cultural and Scientific Organisation (UNESCO) and the World Health Organisation (WHO) defined CBR as follows:

> CBR is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education, vocational and social services.

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1.3 AIMS

1. To conduct community studies in low income communities in Bangalore, Calcutta and Visakhapatnam to explore:
    - the expressed needs and experiences of persons with disabilities and their families in low income communities.
    - their experience of existing services in relation to these needs.
2. To evaluate representative approaches to service provision in the three cities in relation to these needs.

In discussing the aims of the UCBR Project, it is worth clarifying the nature of development of some of the key features of the project; some aspects of what the project did not aim to do; and the meaning of some of the terms used.

- The UCBR Project was concerned specifically with persons with disabilities and their families from low income urban communities.
- This study treats persons with disabilities as a social group rather than as a medically defined complex set of conditions. It therefore does not disaggregate all data by impairmen groups.
- The three cities were selected by the Ministry of Welfare, Government of India so to represent three major size categories of city in modern India. Calcutta, with its population of some 12 million, to represent the metropolitan cities. Bangalore, with an estimated population of 6 million, as one of the second tier cities, and also one with what is described as having the most rapid urban growth in India. Visakhapatnam, with a population of about 1.2 million, represented the third tier of cities., and also had an ODA-funded Slum Imrovement Project with a Disability component.
- The 8 approaches evaluated were selected after an exhaustive process of organisation visits and discussion by members of the evaluation team. For example, in Bangalore, 50 organisations attended a workshop in 1990 to discuss the UCBR project and their possible inclusion as partners. The 8 were selected with the sanction of the Ministry of Welfare to represent a variety of approaches to the delivery of services for and with persons with disabilities in urban areas. Two of the partners (3 and 8 in the table below) are organisations started by persons with disabilities. Two (1 and 7) were started by parents of persons with disabilities. Two (1 and 2) employ approaches based on a professional rehabilitation workers. Two are government, and six are non-government organisations. All except one (6) were included as partners in the UCBR Project because they claimed to be involved with the urban poor. All except one have proven sustainability, having been in operation for over 15 years (and in several cases significantly longer than this).

Table 1: Summary of 8 service approaches selected for evaluation

Organi-sation	**Approaches to service provision**	**coverage group**
1.	**a. Centre based:** out patients department (OPD); special school; vocational training **b. Outreach**	cerebral palsy, and multiple difficulties
2.	**a. Centre based:** OPD; special school; vocational training **b. Outreach**	cerebral palsy, and multiple difficulties
3.	**a. Centre based:** special school; vocational training **b. Community based approach**	a. mainly moving difficulties b.mainly moving difficulties expanding to all difficulty groups
4.	**Home based approach**, with medical referral	all difficulty groups
5.	**Home based approach**, with embryonic integrated approach, with medical referral	all difficulty groups
6.	**Orientation for integrated education**, teacher training	seeing difficulties, multiple

		difficulties
7.	**Special education teacher training**, adult day centre, and insurance	learning difficulties
8.	**Welfare approach**	all difficulty groups

- This study does not specifically examine or evaluate the work of other institutions and services for persons with disabilities in urban areas. However, it approached the work of such organisations where relevant through the perspective of persons with disabilities and their families in low income communities. Thus, this report reflects on other services if they were experienced and commented on by the persons with disabilities randomly sampled in low income communities in the three cities, or by those participating in Focus Group Discussions (FGDs). For example, this study reports on the experiences of the persons with disabilities sampled in the three cities which are relevant to Integrated Child Development Service (ICDS)'s anganwadis, as well as various government medical services in the three cities.
- In this report, the term 'community' is primarily used as a geographical and administrative description. The three community studies depended for their random sample on lists of 'low income communities' in each of the three cities compiled by municipal corporations and allied bodies. For further discussion of the concept of community see section 2.6.5.
- This report presents the needs and experiences of persons with disabilities living in low income communities. Further categorisation within low income communities is used to further explore the coverage of socio-economic groups by the various services evaluated. Thus, within low income communities, there are persons with disabilities that live in pukka[1] houses and those that live in kutcha houses (and the latter are considered to be on average of lower socio-economic status) and there are persons with disabilities living in households headed by a government employee and those headed by a daily labourer, and within this system of classification, the latter are considered to be on average of lower socio-economic status.

1.4 METHODS

The two aims of the evaluation, and the varied nature of the evaluation's stakeholders (government ministries, municipal bodies, disabled people's organisations, and NGOs) demanded that a combination of qualitative and quantitative methods be used. The methods are listed in the following table:

Table 2: Methods

a) Questionnaires
b) Case studies - 'tracer method'
c) Service checklists
d) Document analysis
e) Focus group discussions (FGDs)
f) In-depth interviews
g) Institutional analysis
h) Observation
i) Mapping of service users

The methods were applied in two parts reflecting the division of the project into community studies and service evaluation. The main research instruments are appended. As shown in the literature review, case finding surveys are not useful or relevant and this study was not intended to produce data on prevalence of disability.

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[1] refernce for pukka kutcha

Throughout community studies and organisation evaluations, persons with disabilities were classified according to their difficulties, as described by WHO (1994)[2].

1.4.1 Methods for the three community studies

The three community studies employed complementary quantitative and qualitative methods in low income communities in each city.

1.4.1.1 Questionnaire study

The questionnaire (appendix 1) obtained a representative picture of the socio-cultural and socio-economic situation of persons with disabilities living in a random sample of low income communities and their use of services in relation to their difficulties. Socio-economic status was measured by quality of housing (roof and wall matrials) and occupation of head of household. These proxy measures are widely used internationally and in India (for example by the Ministry of Urban Development). Needs of persons with disabilities were measured by qualitative methods, as a quantitative interview could create expectations which could not be met by the UCBR Project.

The sample size for the community studies was calculated using Epiinfo's 'statcalc' statistical calculator. Using estimated slum populations, sample sizes were calculated using the largest expected frequency of any factor under study of 50% and a worst acceptable result of 40%. The former maximises the sample size. The latter, representing a 10% acceptable difference between expected and observed frequency was necessary given the expected diversity of the population in low income communities and the resources available for the community study.

In each city, a cluster sample method was used. Each cluster was a low income community and clusters were drawn from the best available lists of low income communities in each city. Where necessary, lists were combined to give the most up to date estimate of the number of communities and their relative sizes.

Clusters were sampled by starting at a random point and moving through a list and selecting each *n*th community, where *n* equals the sample interval:

$$n = \frac{\text{total population}}{\text{number of clusters}}$$

Once the sample was drawn up, the most reliable and cost effective means of locating persons with disabilities was through key informants. Fieldworkers visited each community and described the aims of the community study, and the type of people who the study aimed to interview, and asked key informants to help find respondents. This process was time consuming. Also, certain categories of the population were difficult to identify. Each fieldworker could locate and interview a maximum of 4 people per day so qualitative data was collected at the same time. Where possible the questionnaire was delivered in the first language of each interviewee. The schedule was translated and printed in Bengali, Telegu, Tamil, Kannada, and English, and delivered by fieldworkers with appropriate language skills. In total, 587 persons with disabilities and their families were interviewed across the three cities: 200 in Bangalore, 198 in Calcutta and 189 in Visakhapatnam. In each city, approximately 5% of respondents were re-interviewed by a different fieldworker to check the validity of the interview method. Data was analysed using SPSS software.

*Examination of the distribution of difficulty groups in the sample indicates that the key informant method under-identified some difficulty groups, notably those with seeing difficulties (which also included those identified by key informants as 'having seeing difficulties' but who were partially sighted with one eye affected), and those who were both disabled and aged, but in general it does

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[2] World Health Organisation (1994). "Community based rehabilitation and the health care referral services. A guide for programme managers". WHO/RHB/94.1; p.32

not appear that key informants biased the sample towards less severe impairments. This appears to be indicated by the relatively large proportion of those with multiple difficulties included in the sample. For further discussion of the sample population see section *.*.

The sampling method was not designed to fit existing expected proportions of each difficulty group within the population at large. Setting a quota for each difficulty group would have compromised the cluster sampling method used. For example, when fieldworkers visited a community of 300 people, they could expect to find a few persons with disabilities living there based on the expected prevalence of disability of approximately 2% (see section 1..* above). However, if they went with the instruction of finding and interviewing, for example, one person with epilepsy and one person with seeing difficulty in that community in order to fit their quota for each difficulty, the chance of satisfying this instruction would be small. Mixing two contrasting sampling strategies (cluster and quota) is methodologically not advisable.

*The community study questionnaires and evaluation questionnaires were the main tools by which the coverage of services was assessed. Socio-economic, socio-cultural, gender and age data were collected from a random sample of the urban service users from each organisation, and compared with similar data from a random sample of persons with disabilities and their families in low income communities in the UCBR community study in the same city. Given the UCBR Project's aim of advising the Ministry of Welfare on service delivery for the urban poor persons with disabilities, socio-economic coverage was of particular importance.

Socio-economic status can be measured in several ways. The most obvious measure is income. It is reported that income is used as a measure of socio-economic status by the Planning Commission, Government of India, State Government, Public Works Department, and Department of Food. It has also been used in research, and data on income is maintained by some of the partner organisations specifically for the distribution of progressive concessions. However, income was not used to measure socio-economic status in the UCBR project for several important reasons. Estimating household income is problematic when contributions to a common household budget are made by multiple household members, and where working patterns, and income, are variable and/or seasonal, which are particularly common in low income households. Estimates of income by households may also be unreliable if benefits are given in relation to this estimate; people will tend to underestimate their income in the hope of securing more benefits. During the evaluation period, this problem was acknowledged by several of the partners and by some service users. Household income is not a good indicator of socio-economic status if the number of people sharing that household income is not considered. In the UCBR project, income was also particularly unsuitable given the length of the fieldwork period. The community studies and evaluations took place over a two year period. With an annual inflation rate of around 10%, data collected in an evaluation at the start of the fieldwork period would not be easily comparable with that collected in a community study at the end of the following year.

Given the difficulties of using income as a measure of socio-economic status, an alternative is the use of household expenditure. However, this method is also problematic. Recall of expenditure is acknowledged to be often inaccurate, in India and elsewhere. The alternative approach, which uses prospective expenditure diaries, has been found to be unsuitable if respondents are non-literate. Thus, in the UCBR community studies, which focused exclusively on low income communities, the use of expenditure as measure of socio-economic status was not considered appropriate.

An alternative to the use of income and expenditure to measure socio-economic status is the use of proxy indicators. Proxies should have a high correlation with income. Two of the most common types of proxy indicators of socio-economic status are household environment and occupation type. Aspects of household environment which have been used as proxy socio-economic indicators include number of rooms, access to water supply, access to sanitation, and reporting factual, rather than perceptual information. Perceptions and feelings were explored through qualitative methods. Qualitative data are presented in the form of direct quotations from persons with disabilities and their families. For brevity, only one example has been included to describe issues raised, but each is representative of common statements made across the three cities. The findings of the community studies are organised in a question-and-answer structure, and with reference to barriers to service use. The symbol '☹' has been used to indicate discussion of different barriers.

1.4.2 Methods for evaluation of the service approaches

The aim of the UCBR project's evaluation of eight service organisation was to evaluate services in relation to the experiences and needs of persons with disabilities from low income communities which were measured in the relevant community study. The measures used in the evaluations with partner organisations are summarised in the following table:

Table 4: Evaluation measures

	Measure	***Explanatory Notes:***
1.	Objectives	organisation's objectives - against which each is evaluated
2.	Status	funding sources, relationships with donors
3.	Model	model of service provision
4.	Coverage	coverage of services - spatial, socio-economic, gender, and socio-cultural.
5.	Cost	i) cost of service provision, ii) costs to user
6.	Staff structure	management structure, representation and participation of persons with disabilities and staff at different levels
7.	Community attitudes	attitudes of the community toward persons with disabilities, from persons with disabilities perspectives
8.	Staff attitudes	attitudes of organisation staff toward persons with disabilities and disability as an issue
9.	Range of services	types of services provided
10.	Quality - medical rehabilitation	including a functional perspective, and technical, interpersonal and management quality.
11.	Quality - education	including formal and informal approaches
12.	Quality - employment and training	including orientation of vocational training, work opportunities and outcomes
13.	Quality of life	from the perspective of persons with disabilities
14.	Audit	review of user records and financial records
15.	Convergence	relationship with other services used, or available
16.	Participation	as a value, for service users *and* all staff
17.	Sustainability	including finances, support in the community, and within the organisation
18.	Differences between organisations staffed by persons with disabilities with those staffed by non-disabled people.	is there any difference in services, attitudes, of staff who are persons with disabilities and those who are non-disabled people
19.	The awareness of staff of disability as a socio-political issue.	including awareness of the relationships between poverty and disability
20.	The role of advocacy and self advocacy in the organisation.	Ranging from persons with disabilities as passive consumers of services, to empowerment to assert rights as citizens and gain access themselves

1.4.2.1 Quantitative method

A questionnaire (appendix 3) was administered to a random sample of the persons with disabilities and their carers using four of the eight rehabilitation approaches evaluated. The sample was limited to those coming from urban areas. The other four did not have service users of types amenable to a questionnaire based on service use sessions, or numbers were too small to suit a random sample survey. Instead, in-depth interviews were used.

For each organisation in which the questionnaire was applied, the sample size was based upon the estimated number of users attending all services provided by that organisation. This was devised from available records. As in the community study, the sample for each organisation was calculated using Epiinfo Statcalc. The number of persons with disabilities sampled within each service was proportional to the total number of users of that service. Where possible, samples were drawn at regular intervals from available lists of users, starting at a random point. Where it was impossible to know who would attend on a particular day, samples were drawn by interviewing all those attending from urban communities until the sample proportional to the total number of users for each service was reached. This assumed that the people attending in that period were representative of users throughout the year. *In total, the questionnaire interviews took place with a random sample of 492 service users.

1.4.2.2 Qualitative methods:

Separate focus group discussions (see appendix 4) were held with persons with disabilities using each organisation, their family members (in separate FGDs), and with the staff of the service organisations divided by gender, and age. *In total, 40 FGDs, including 240 people, explored; expressed needs; socio-economic and socio-cultural information; experiences and perceptions of the particular service under evaluation; and experiences of other services.

Table 5: Description of participants in evaluation FGDs

1. Special school senior academic girls
2. Special school senior academic boys
3. Vocational training female trainees
4. Vocational training male trainees
5. Education service mothers of children with disabilities
6. Special school mothers
7. Special school fathers
8. Adult service parents
9. Parents group mothers #1
10. Parents group mothers #2
11. Parents group fathers
12. Female Vocational training trainees
13. Male Vocational training trainees
14. Mothers of Disabled Children, outreach #1
15. Fathers of Disabled children, outreach #2
16. Outreach girls with disability
17. Persons with disabilities on staff
18. School boys
19. School girls
20. Outreach social workers #1
21. Outreach social workers #2
22. Youth Group of persons with disabilities
23. School students #1
24. School students #2
25. Vocational training students
26. Vocational training parents
27. Carers of persons with disabilities, outreach service
28. Outreach staff #1
29. Outreach staff #2
30. Physio aides
31. Senior Therapists
32. Outreach parents of children with disabilities, centre #2
33. boys with disabilities
34. girls with disabilities
35. young women with disabilities
36. mothers of children with disabilities
37. mothers of children with disabilities
38. fathers of children with disabilities
39. CBR workers before evaluation period
40. CBR workers at end of evaluation period

FGDs were complemented with ongoing interviews with service users and staff, both formal and informal in nature; case studies; and observation throughout the evaluation period.

1.4.2.3 Tracer method:

The quality of medical rehabilitation inputs was assessed using a tracer method. This multi-faceted method was applied to service delivery sessions, for a small sample of persons with disabilities, all from low income households. It addressed the degree to which needs were met, interpersonal, and technical quality. See appendix 5 for more details.

1.4.3 Presentation and discussion of key findings and draft policy recommendations

Analysis of data and preparation of reports was followed by a cycle of presentations and discussion at workshops held in each of the three cities. Key findings and draft policy recommendations were presented and the discussion incorporated in the draft recommendations presented at the next workshop in the cycle. This process culminated in the presentation of draft recommendations at a National Workshop in New Delhi under the Ministry of Welfare. Key aspects of the discussions at the four workshops have been incorporate in this final report.

*1.5 Description of community study sample

1.5.1 Difficulty groups

The representation of different difficulty groups in the sample is described in Table 6. These frequencies of difficulty groups are not intended to represent their relative prevalence in low income communities. Rather, they are listed here to describe the group of persons with disabilities and their families interviewed in the community study survey.

Table 6: distribution of difficulty groups in the community studies

Difficulty Group	***freq***	***%***
1. moving difficulty - polio	152	26%
2. moving difficulty - other	120	20%
3. learning difficulty	42	7%
4. epilepsy	17	3%
5. speech and/or hearing difficulties	84	14%
6. multiple difficulties	124	21%
7. seeing difficulty	41	7%
8. other (e.g. leprosy)	7	1%
TOTAL	***587***	***99***

All respondents were asked if they knew the history and diagnosis of their difficulty. From the qualitative notes taken, some of those described as having learning difficulties actually had mental illness.

The use of classification by difficulty in this study (see justification on page *) makes direct comparison of the sample data with existing data on the relative proportions of different 'disabilities', such as the National Sample Survey (NSS) of 1991, impossible. The NSS estimates the number of persons with disabilities and the relative proportions of different disabilities, but leaves out learning difficulty (or 'Mental Retardation') and epilepsy and does not account for people with multiple disabilities within the data. The NSS's general definition of disability ('any restriction or lack of abilities to perform an activity in the manner or within the range considered normal for human being') is not comparable with the definition of 'difficulty' used in this study, and the definitions of different 'disabilities' are more specific than used in this study. Three of the five categories used in the NSS describe various communication difficulties. Table * presents the relative proportions of different groups in the NSS, with an estimate for 'Mental Retardation' based on expected frequencies reported by Baquer and Sharma 1997; p.39[5]:

Table *: National Sample Survey (1991) - estimated numbers of disabled persons

Type of Disability	***n (millions)***	***%***
Visual	4.005	13.9
Hearing	3.242	11.3
Speech	1.966	6.9
Hearing and/or speech	4.482	15.6
Locomotor	8.939	31.2
'Mental Retardation' (moderate, severe, or profound).	6.00	20.9
Total	28.634	100

It should be noted that in the UCBR Project sample'multiple difficulties' (see table 6 abve) includes people with combinations of moving and learning difficulties, moving and communication difficulties, etc. This accounts for some of the difference between the two tables. In general, the key informant method over-represents those with moving difficulties, probably as these are the most visible group in the community.

Other available data collected shows markedly different relative prevalence when compared with the NSS, depending on the means of collection. For example, a review of annual assessment camps in the state of West Bengal gives the following data: 'orthopaedic' (45%); visual (20%); speech (10%); hearing (15%) 'mental retardation' (5%) cerebral palsy (2%) and leprosy cured (3%)[6].

1.5.2 Gender

Table 7: Gender distribution of community study samples

	male	***female***
Bangalore	105 (52%)	95 (48%)
Calcutta	125 (63%)	73 (37%)
Visakhapatnam	102 (54%)	87 (46%)
Total	***332 (57%)***	***255 (43%)***

The fieldworkers were instructed to interview male and female persons with disabilities; key informants directed them to more males. This may reflect the population of persons with disabilities at large, or may reflect the greater visibility of males with disabilities in the urban community. There was no relation between gender and the types of difficulty represented in the sample.

1.5.3 Age

The sample included a wide range of age groups, including older people.

Table 8: Age distribution of all persons with disabilities interviewed in community studies

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[5] Baquer, A and Sharma, A (1997) Disability: Challenges Vs Responses. Concerned Action Now (CAN): New Delhi

[6] De, A (1997) Early childhood impairments - role of anganwadi workers in ICDS. Presentation by Ex-Director of Social Welfare, Government of West Bengal (***check GC) to the ******.

Age groups	***total freq***	***%***
1-5 years	58	10
6-10 years	117	20
11-15 years	118	20
16-25 years	146	25
26-55 years	128	22
>56 years	20	3
Totals	**587**	**100**

The sampling method, with its reliance on key informants, did not successfully represent those who are disabled and aged, particularly people with later-onset seeing difficulties. For some older people, such impairments may be taken for granted, both by themselves and by other community members (including key informants). In the community studies, on at least three occasions, people with difficulties who were over the age of 65 were observed to be ignored by the key informants. In discussion they themselves did not regard that they fell within the group of 'persons with disabilities' as they differentiated between late onset impairments associated with old age and persons with disabilities in general.

*** age distribution in cities

1.5.4 Socio-economic status

As described in section *, socio-economic status was assessed using two proxy socio-economic indicators; housing material and occupation of household head.

Table 9: Socio-economic classification using housing materials as a proxy indicator

Housing classification	***Calcutta***		***Bangalore***		***Visakhapatnam***	
	freq	*%*	*freq*	*%*	*freq*	*%*
pukka	35	18	30	15	20	11
semi pukka	10	5	75	38	13	7
semi kutcha	98	50	19	10	76	40
kutcha	55	28	76	38	77	41
no shelter	*0*	*0*	*0*	*0*	*1*	*1*
missing data	*0*	*0*	*0*	*0*	*2*	*1*
Total	**198**	**100.0**	**200**	**100**	**189**	**100**

The second proxy was household head's occupation, and was classified into the groups described in table *.

Table 10: Socio-economic classification using occupation of household head as a proxy indicator

	Calcutta		*Bangalore*		*Visakhapatnam*	
Work classification of household head	*freq*	*%*	*freq*	*% (valid %[7])*	*freq*	*%*
unskilled labour	69	35	97	49 *(54)*	82	43.4
skilled labour/craft	59	30	36	18 *(20)*	40	21.2
petty business	32	16	26	13 *(14)*	17	9.0
machinery operator	15	8	6	3 *(3)*	11	5.8

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[7] *-As data is missing for 20 of the respondents due to fieldworker error, the percentage excluding the missing data has been included in brackets.

clerical	3	2	2	1 *(1)*	22	11.6
government employee	8	4	6	3 *(3)*	9	4.8
business	5	3	1	1 *(1)*	0	0
pension	6	3	4	2 *(2)*	1	.5
Other requiring higher education	0	0	2	1 *(1)*	5	2.6
missing data	1	1	*20*	*10.0*	2	1.1
Totals	***198***		*200*		189	

As described in section *.* above, there is a correlation between these two proxy socio-economic indicators. Tabulating occupation of household head (manual versus non-manual) and housing materials (the pukka: kutcha system) gives a significant relationship in the three cities: Calcutta (Chi^2=11; df=1; p=0.00090): Visakhapatnam (Chi^2 =25.29143; df=4; p=0.00004): and Bangalore (Chi^2=10.38; df=3; p=0.015).

SECTION 2 SUMMARY OF COMMUNITY STUDIES: NEEDS AND EXPERIENCES OF PERSONS WITH DISABILITIES IN LOW INCOME URBAN COMMUNITIES

2.1 SUMMARY OF NEEDS

The specific needs of persons with disabilities and their families in low income urban communities in order of priority are for:

1. Work and income
2. Education
3. Appropriate medical rehabilitation
4. Inclusion in urban community development
5. Acceptance in the community

Many of the needs expressed can be related to improved socio-economic status, which is common to many households in low income communities.

*The Disability Act 1995 divides the various issues related to the lives of persons with disabilities into five broad categories, namely:

a) Education
b) Medical attention and health (physical rehabilitation)
c) Social security
d) Barriers to access - physical and social
e) Economic rehabilitation.

These are presented without any priority. However, it is notable that several of the needs expressed by persons with disabilities in the UCBR project fall into the categories in the Disability Act. With regard to barriers to access, these form a major part of the frame for the discussion of the findings of this report. To physical and social barriers (described below as 'environmental' and 'attitudinal' are added 'economic' and 'structural' barriers.

There are few if any similar studies of the needs of persons with disabilities and their families in urban low income communities in India with which to compare this study. One study of needs is described in Peshawaria et al (1995; p.79)[8], who explored the needs expressed by families (parents and siblings separately) of those with learning difficulties, using individual interviews in which respondents ranked listed needs during individual interviews. The study found that the needs which were most 'endorsed' by parents were for the following (with the 'percentage endorsement' listed):

1. Government benefits and legislation (93.6%);
2. Vocational planning (89.0%);
3. Information [about the] condition (86.9%)
4. Future planning (84.4%)
5. Services (83.6%)

However, it is difficult to relate this data to the present study as the sample was quite different. As well as being specific to "Mental Retardation", Peshawaria et al[8] describe a sample of 218 parents (from 120 families) of which 49.1% have education to degree level or above, and the sample mean family income is over Rs.3000 per month. They also describe that 79 of the 120 families were living in urban areas, and 41 of the 120 (34%) "were living in rural and slum areas". Finally, the sampled families were sampled through the services that they were already using. However, it is of interest to note that Peshawari et al found that "as the education level of the parents increases the reported parental needs decreased. Least educated parents (primary and below)

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[8] Peshawaria R, Menon, DK, Ganguly,R, Roy,S, Pillay,R, and Gupta,A. (1995) Understanding Indian Families Having Persons with Mental Retardation. National Institute for the Mentally Handicapped, Ministry of Welfare, GoI. GA Graphics: Hyderabad.

were found to report significantly higher needs in areas such as 'Information', 'Hostel', 'Financial', and 'Marriage'" (Peshawaria et al 1995; p.89).

2.2 NEEDS AND EXPERIENCES OF WORK AND INCOME

> "Money is everything. If we have that, then we will automatically get respect".
> *Woman, 42, with moving difficulty following stroke. FGD1.9 Bangalore*

i) Employment: The need for employment was clear. People in all three cities asked if the fieldworker would help them to get a job, particularly as the fieldworkers introduced the project as being on behalf of the Ministry of Welfare. There was however, little insistence in this demand as unemployment was common for disabled and non-disabled people alike. Adults with moving difficulties, particularly from polio, described how they were job seeking, and expressed the need to find employment suited to their abilities; typically a job where they could sit down, in assembly work for those with little education, or office work for those who had passed higher standards. Office jobs were favoured by most unemployed people; non-disabled family members also wanted to find a job in an office, even if they already did manual work. This competition reinforces the need for education if persons with disabilities are to find employment.

ii) Job skills training: adults with disabilities interviewed expressed a need to learn job skills as well as academic education to improve chances of employment. Some persons with disabilities interviewed were still unemployed despite undergoing several types of training and they stressed that the success of training should be measured in terms of finding economically productive work.

Iii) Loans for self employment: In the absence of work, people sought access to loans to provide start-up capital for small businesses. This included both for persons with disabilities, or for family members, particularly of those with severe and multiple impairments. In the latter group, families described a need for income so to be able to support their disabled family member. Some people, typically mothers, were supporting their disabled family member full time and as a result were unable to go out and work. Some had considered starting a small home-based business so that they could be available to support their disabled family member and also earn some money. The major barrier to doing this was a lack of access to start-up capital. They were unable to raise the money needed within their circle of contacts, and did not want to borrow from local money lenders.

iv) Pensions: Some parents expressed direct financial needs, to help support the person with disability and the rest of their family:

> "Please give me some money or I'll put her in a home. I earn less than Rs.500 per month, and her father has never given me anything to help bring up his daughter".
> *grandmother of woman, 25, with severe moving difficulty.*

Some of those interviewed were aware of government pensions for persons with disabilities, and requested assistance in applying for them as they did not know where to go, or expected that the application would be difficult for them to complete.

Question 2.2.1: what are persons with disabilities' experiences of work?

Of the 294 persons with disabilities over the age of 15 interviewed in the community studies, 34% were doing paid work. None was working in segregated jobs or segregated environments reserved for persons with disabilities: all were working in mainstream activities in the economic life of low income households, such as keeping petty shops, home-based piece work, and rag picking. The distribution of paid work by difficulty groups is summarised in the following table:

Table 11: Number of persons over the age of 15 with disabilities doing paid work in three cities

difficulty group	*In paid work*	*Not in paid work*	*Total*
moving difficulties - polio	33	31	64
moving difficulties - other	31	51	82
learning difficulty	1	13	14
epilepsy	4	6	10
speech and/or hearing	12	23	35
multiple difficulties	3	51	54
other difficulty	3	4	7
seeing difficulty	13	15	28
Column totals	*100 (34%)*	*194 (66%)*	*294*

Those with moving difficulties appear most likely to be in work. Persons with multiple difficulties (severe and multiple impairments) were particularly unlikely to be in paid work.

In Calcutta and Visakhapatnam, men with disabilities were significantly more likely to be doing paid work than women. Earning money was expressed as a need for men and women. During qualitative interviews, many women with disabilities reported that they do household work, even if they have difficulty in moving around the house or other difficulties.

answer: 34% of adults with disabilities were doing paid work, all in mainstream occupations. In two cities, men were significantly more likely than women to be working.

Question 2.2.2: what are the barriers to work?

Of those who were working, most described the experiences common in mainstream, though low paid jobs. Some expressed that they were unable to do labouring jobs, and described that employers had refused them a job because they were disabled. Problems at work related to peoples' disabilities were rare, partly because most were either 'self employed' or employed in small businesses close to home and so well acquainted with their fellow workers, who were family, friends, or neighbours. A handful of adults across the three cities described having been paid less for their work than non-disabled workers. A few of those with learning difficulties were described as having inadequate skills for work that they had tried.

answer: barriers related to difficulties in labouring jobs, or lack of appropriate skills. few described barriers related to the attitudes of employers or other workers.

Question 2.2.3: is begging a common means of earning money?

Of the 587 persons with disabilities interviewed in the three cities, four described that they begged to earn money. All four stated that it is difficult to beg enough money to live on. None begged through choice; it was their only means of earning money. Two had tried other means of earning money but because of barriers to other work had been forced to beg.

> "I studied in a mainstream school in Bihar until I was 8, but then had the accident. Since then I go to beg on the roads and earn Rs.10 or 20 per day.. this is the only source of income for the family. I don't go out to beg everyday, it depends on my mood".
>
> *boy, 15 , with moving difficulty. Calcutta 085*

In this study, there is no evidence whatsoever to suggest that impairments had been caused deliberately in order to provide persons with disabilities for organised begging operations, or that persons with existing impairments had been recruited into such operations.

answer: begging is not a common means of persons with disabilities earning money

Question 2.2.4: what are experiences of training for work?

In the three cities, 46 of the 294 persons with disabilities over 15 interviewed had received training for work. 38 of these had been trained in the mainstream workplace in which they worked. The number of people who had been trained in vocational training for persons with disabilities was far less than the number of mainstream trainees: just 8 of the 46 had received segregated training. Like work opportunities, routes into training were also those of the mainstream such as through relatives, and friends. Of the four that had received training in vocational training centres in Visakhapatnam and Bangalore, none had found work after training. For a full breakdown of the places in which the persons with disabilities had trained refer to appendix *).

answer: 15% of adults interviewed had undertaken training for work, mostly in mainstream workplaces.

Question 2.2.: what are experiences of the Vocational Rehabilitation Training Centres (VRCs)?

Vocational Rehabilitation Training Centres

The Ministry of Labour, Government of India, is concerned with the economic rehabilitation of persons with disabilities through the network of Vocational Rehabilitation Training Centres (VRCs). The Ministry reports that the capabilities of persons with disabilities are assessed, vocational training suggested or imparted, and persons with disabilities rehabilitated either in regular jobs, self-employment, or any other gainful employment. VRCs also organise special camps to look into aspects of the labour market, rehabilitation needs, assessment of individual persons with disabilities and involvement of NGOs. VRCs also undertake experiments in community based vocational training and rehabilitation. In 1997 there were 17 VRCs in India, 2 of which were for women only. VRCs are located mostly in state capitals and "act as models for the State Governments to set up more centres depending on their needs[9]". At 7 of these centres, skill training facilities have also been provided as an extension of rehabilitation services. The Sixth Plan period covered the rural population and 11 Rural Rehabilitation Extension Centres were provided at the Block Headquarters level, attached to 5 selected District Rehabilitation Centres (DRCs). Each year the 17 VRCs are reportedly able to rehabilitate 7,000 persons with disabilities, an average of some 412 per centre.

An example of a VRC is that in Calcutta. It is situated near Salt Lake on the Eastern edge of the urban area. It offers centre based training. There are no hostel facilities and training requires daily attendance. An allowance of *Rs.125 (*check current*) is available for trainees. The VRC undertakes a vocational assessment of persons with disabilities, and helps them to choose a trade, and is reported to assist them in finding placement on completion of training (*** more details to come).

The UCBR Project did not specifically examine training under the VRCs; rather, it approached training from a community based perspective by randomly sampling persons with disabilities in low income urban communities in three cities and recording their experiences of training, if any. In the three community studies, 46 (16%) of the 294 persons with disabilities over the age of 15 years who were interviewed had received training for work of some sort. However, none of these had undergone training at VRCs.

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[9] Baquer, A and Sharma, A (1997) Disability: Challenges Vs Responses. Concerned Action Now (CAN): New Delhi

answer: None of the 294 adults with disabilities sampled had undergone training at the Ministry of Labour's Vocational Rehabilitation Centres for Handicapped (VRCs).

Question 2.2.5: what are persons with disabilities' experiences of government welfare provision?

The community studies indicate that the coverage of government welfare benefits is small and varies in quantity and quality between cities:

Bangalore: 16% of persons with disabilities had obtained welfare benefits. Seven children had government scholarships; 25 people had pensions; and 1 had a place in a government remand hostel. One person reported that they had a bus pass.

Calcutta: 29% had obtained welfare benefits. 1 government disability scholarship; 3 government pensions; 23 handicapped cards; 8 disability certificate (but no card); and 8 bus passes.

Visakhapatnam: 32% had obtained welfare benefits. 58 had a bus pass. None had a government pension.

Gender and socio-economic status have no apparent effect on access to these welfare services. In theory, medical certificates and handicapped cards are the instruments with which to access other benefits but in many cases they are ends in themselves, as no material benefits are gained.

answer: 25% of persons with disabilities have accessed government welfare benefit. Access varies between cities.

Question 2.2.6: what are the barriers to government welfare services?

Many of those interviewed did not know of the existence of benefits, or described a lack of information about how to access them. After this come the barriers experienced during application. These were non-availability of services such as bank loans; the negative and obstructive attitudes of some government employees; and unofficial costs of availing a service, including bribes. Other people were aware of the limited services available with a certificate and card and did not think it worthwhile to try and get a medical certificate.

The government welfare provisions which are theoretically available to persons with disabilities are: bus and train passes; disability pensions; school scholarships; bank loans for small business; and registration at special employment exchanges for government jobs reserved for persons with disabilities. Application for these demands a medical assessment at a government hospital. If the degree of disability is assessed as being of 40% or over, the individual can apply for a handicapped card issued by the Department of Social Welfare.

In Calcutta 12% of respondents had a handicapped card. 8 others had a disability certificate but had not got a card. Application is shaped somewhat by age (for example, babies, travelling free on busses, are not usually regarded as needing to apply for a bus pass) and degree of difficulty (those assessed as under 40% disability do not get a card) but this coverage is still surprisingly low.

Respondents described numerous barriers to accessing government services in general. The example of medical certificates indicates the barriers to all government welfare services. Barriers can be classified into economic; environmental; structural; and attitudinal.

i) Economic Barriers:

☹ **bribes demanded by government employees**: persons with disabilities in all three cities described being asked for bribes during application. For example, one man made the following allegation:

> "I got a Handicapped Certificate from Barrackpore Hospital, but had to pay Rs.500 for this. The money was shared by the tout and by the doctor. I request that you take action against such government servants and arrange for me to get the money back. In the handicapped office the staff don't want to listen to us. How can we rely on government if we are handicapped? None of the staff are concerned about us and they treat us like dogs". *man, 25, with moving difficulty. 145*

☹ **payment of touts**: Paying a local tout to access government services was a means of overcoming the barriers described below.

☹ **cost and time taken for multiple visits to government offices**

ii) Environmental barriers:

☹ **difficult physical access to government offices.**

iii) Structural barriers:

☹ **absence of other supporting documents such as ration cards**.

☹ **no information about where to apply**.

☹ **medical assessment of less than 40%.**

iv) Attitudinal barriers:

☹ **negative attitudes of government employees**.

> "I have very little sight in my eyes. I use glasses, and with their help I can see up to 5 feet away but only shapes. I once went to a government office to apply for a pension and I had the medical certificate showing over 40%, but they chased me out, saying that they didn't believe that I am blind". *man, 20, with seeing difficulty. Bangalore 139*

Thus, application for a disability certificate and handicapped card is difficult. These barriers are multiplied by the fact that cards have to be renewed every few years, thus the same barriers are met again. Experiences specific to other welfare services are described below:

Bus passes: Many of those who had got bus passes reported that they are not allowed to use them on government buses. They were unsure of their rights and so rarely argued when a bus conductor ignored their pass and demanded money. Some parents had obtained bus passes for their disabled children, but had never used them as their child had to be carried and had become too difficult to lift onto the bus.

Loans for self employment: Of the 587 persons with disabilities interviewed in the three cities, 3 had secured a loan for income generation. All three were exceptional cases; they were educated men with considerable family resources. Others persons with disabilities had considered the idea of a loan but did to know where to apply. Officially, bank loans are available to persons with disabilities. Loans for family members of persons with disabilities are unavailable.

Government pensions: Pensions are officially available for those over the age of 18, and those under 18 who are not in education. Qualification demands a disability certificate showing the appropriate percentage of disability as assessed by a government doctor (usually 40%). Overall, of the 237 adults interviewed, 28 (10.5%) had obtained a pension. In Calcutta, 4 of 107 adults had a pension; in Bangalore, 25 of 51 had a pension; in Visakhapatnam, none of the 79 adults interviewed had a pension. In Calcutta two of the four with pensions had accessed other government facilities, and were doing paid work. This, and the account of how they got pensions, suggests that pensions are not always distributed equitably:

> "I earn Rs.200 to Rs.300 per month. Rs.200 comes from tuition which I do for local school children and Rs.100 from my government pension as a handicapped person... In the evening I go to a computer class for training... I didn't face any problem in getting the handicapped pension. I got my first pension 6 months after applying and have been receiving the pension since the last one year. I have a contact in the Writers' building and so I have got it very easily. The staff in the pension office said to me: 'You are very lucky to get it so easily - you have got it ahead of the 500 applicants waiting to receive the pension'". *man, 24, with moving difficulty. Calcutta 133*

A further barrier in Bangalore was the demand for payment by postal workers in return for delivering the pension. People paid this as they feared they would lose the pension if they did not.

Registration at Special Employment exchanges: In Bangalore and Visakhapatnam none of the persons with disabilities interviewed had registered at the special employment exchange. In Calcutta, of 9 of the 113 adults interviewed, had registered. However, none of the adults interviewed in the three cities had gained employment through this provision. There were reports of bribes being demanded for applications within the government disability quota:

> "Somebody came and told me that there was a job under the disabled quota in the Indian Railways, and they told me to apply. The people wanted a lot of money for the job and since I didn't have that much money I couldn't avail the chance. I spend most of the time at home just sitting".
>
> *man, 32, with moving difficulty from leg amputation. 159*

answer: the coverage of government welfare provision is limited and it does not reach those most in need. Welfare provision is characterised by barriers to access. There is a general lack of information about benefits, and for those that do apply, the poor attitudes of government employees, and the bribes that they demand, are the greatest barriers.

2.3 NEEDS AND EXPERIENCES OF EDUCATION AND LEARNING

In discussion in the three cities, education was explicitly linked to increasing employment opportunities and socio-economic independence. Some considered the need for education to be greatest for children with disabilities as they would be less able to find manual jobs than their non-disabled peers:

> "He sometimes helps in sweeping, cooking and washing utensils. I am interested to educate him, as only if he is self dependent economically can we think about his marriage". *mother of boy, 15, with moving and hearing difficulty. Calcutta 185*

A few persons with disabilities stated the need for financial assistance in education, but few knew of, or mentioned government scholarships. The parents of many of the children with moving difficulties want their children to do well at school. Families of children with severe and multiple impairments expressed needs relating to more fundamental learning, such as self management skills, including toiletting, washing, and feeding, and basic education skills, to enable the person with disability to increase their control over their own life. A few family members said that this would improve their loved ones' quality of life in the home, but more hoped that something could be done to reduce their dependence on the time and effort of other family members. This would allow family members to do other things, particularly go out to work. Other families described needs for help in addressing children's unacceptable behaviour. Two major concerns were described. Firstly, violent behaviour, in which someone else might get hurt but equally resulted in the person with disability being beaten by others. Secondly, the safety of young girls and to a lesser extent boys who roamed about the community. In all three cities, some families resorted to tying the person with disability up to stop them "getting into trouble".

Question 2.3.1: what are the experiences of persons with disabilities in education?

a) *Integrated Child Development Services (ICDS)'s anganwadi centres

In 1997, the ICDS network was reported to consist of 3097 project covering nearly 70% of India's community development blocks and 260 urban slum pockets. Baquer and Sharma (1997) report that:

> **Integrated Child Development Services**
>
> "In spite the conviction of policy and planners, children with disabilities remain marginalised in the ICDS programme and its activities. A sizeable number of children often remain undetected and there is little co-ordination between health and ICDS functionaries leading to sporadic efforts in immunisation, health check-ups and educational activities.
>
> There is no integration in the anganwadis and children with disabilities grow up in an environment indifferent to their real needs. The anganwadi worker has limited understanding, skill and knowledge in arranging pre-school activities and her limited sensitivity is unable to integrate the children with disabilities in the pre-school activities. Due to its reliance on voluntary efforts, ICDS has been able to keep down its implementational costs but the low honorarium paid to the anganwadi workers is a major impediment to sustaining motivation. They feel overburdened with responsibilities and tend to concentrate on services that are more closely monitored, such as supplementary nutrition distribution, immunisation etc. A recent study by the National Institute of Nutrition indicated that 40-50% of anganwadi workers in Andhra Pradesh could not distinguish backward children from normal with respect to their psychological development.
>
> In three months training of anganwadi workers, only two days are allotted to orientation on symptoms of disability, suitable play activities, availability of aids and appliances for them. However, the present arrangements of training remains localised to the areas which are services by the 11 institutes that handle their training. Disability has been introduced into the second phase of the three phase sandwich programme."
>
> *Baquer and Sharma (1997; p.114-115)*

Available descriptions of the role and practice of anganwadi workers with regard to children with disabilities, including training material for anganwadi workers, focus on prevention, identification and referral. Indeed, accounts stress the limitations of the anganwadi worker in the rehabilitation process:

> "[*the anganwadi worker*] has her own limitation. Unless she gets the support services for referral, she will not be successful. Further, AWW cannot should not be expected to provide rehabilitative service for the management of the mentally retarded, hearing/speech impaired. She can detect, prevent, educate and refer but can never treat and rehabilitate" *(De 1997[10])*

This study did not specifically address the coverage of children with disabilities by anganwadi centres under the ICDS scheme. The sampling method used in the community studies included persons with disabilities of all ages, therefore was not particularly suited to address questions specifically addressing the service use of pre-school children as the sub-sample falling in the

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[10] De, A (1997) Early childhood impairments - role of anganwadi workers in ICDS. Presentation by Ex-Director of Social Welfare, Government of West Bengal (***check GC) to the ******.

under 6 age group was just 9% of the total sample. However, some children between the ages of 2 and 5 years inclusive, which includes the core group served by anganwadi centres, were included in the random sample and thus some data is available.

******If available comparison of list of community sample communities and coverage of the anganwadi centres in the cities ******

In Bangalore, of 33 children with disabilities between the age of 2 and 5 inclusive, 24 had received no educational input. Of the 9 who were attending some sort of education service; 3 were attending anganwadi, (1 child with moving difficulty and epilepsy; 1 with polio related moving difficulty; 1 with epilepsy) 4 were attending private nurseries; 1 was attending mainstream school (standard 1) and 1 was attending a special school.

Of the 15 children with disabilities in the Calcutta sample who are aged between 2 and 5 years inclusive, 2 had some attended some form of education (one 5 year old girl with moving difficulty following burn injuries was in standard one of a mainstream school; one 5 year old boy with moving difficulty following polio attended an informal class in a local Congress club). 13 of the 15 had never attended any form of education . This group included 12 children aged between 3 and 5 years - the core IDS age group.

In Visakhapatnam, none of the 7 children sampled in the 2 to 5 age group had ever attended any form of education service. This group includes 2 with polio, 1 with learning difficulties, and 4 with multiple difficulties.

In summary, of 55 children in the age group of 2 to 5 years inclusive which is the expected coverage age group of ICDS, 44 (80%) had never used any educational service. 4 children (all in Bangalore) had attended anganwadi.

b) Primary education:

Primary education officially extends from over 5 to 10. However, children often register later and finish later than 10, or drop out at any age. Therefore, examination of coverage of education for persons with disabilities focuses on those over the age of 5, and on a current school age population aged between 5 and 15 years. All persons with disabilities over 5 years old were asked "have you ever been to school?". 309 (57%) of the 540 people had been to school at some time. 43% had never been to school. Comparable data for urban children in general is scarce. Percentage data for those living in low income urban communities is unavailable. The average figure for all children in the 5 to 14 age group in urban West Bengal, Karnataka and Andhra Pradesh combined can be crudely estimated for 1987-88 as 72%[11]. Thus, it appears that children with disabilities are less likely to have been to school than the population in general.

With regard to the learning needs of those with multiple and severe impairments, the three community studies found that pursuit of rehabilitation is typically medically oriented and involves considerable effort and cost, but rarely meets their real needs, particularly as age increases. This disparity between need and service delivery is most apparent with regard to self management skills. Few respondents had received inputs for these needs: rather, their experiences of medical rehabilitation focused on diagnosis, mobility (where appropriate), and prevention of further deformities. Positioning for improved function was described by some, but this was limited to sitting and not associated with activities. Learning needs relating to unacceptable behaviour were unaddressed.

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[11] Calculated from data of National Sample Survey Organisation, Government of India (1992). In *Report of the Education Commission, Government of West Bengal.* August 1992.

☹ **cost:** costs may be incurred for purchase of uniform, books, and private tuition.

ii) Environmental barriers:

☹ **poor physical access:** a few people described transport and mobility as a barrier. Some with moving difficulties described difficulties in physical access while at school.

Iii) Attitudinal barriers:

☹ **lack of motivation to complete education**: Other persons with disabilities from poor families leave school when they lose interest and there is little motivation from teachers or parents to encourage them to continue with studies.

☹ **parents' perceptions of disability as a barrier to school attendance:** some persons with disabilities had never been to school as their parents had not thought education possible for children with disabilities. When asked about education, they expressed surprise that anyone would ask, as their child was "too disabled" for school.

☹ **negative experiences at school:** Others had left school because of negative experiences. These included abuse by other students and dissatisfaction with the quality of education.

> "I faced psychological harassment when I used to study in school. My classmates teased me, they would to say, 'You are not going to get married because of your deformity'. They also make fun of my difficulty, so I became very irregular in attending classes. My mother complained about it to the school principal who punished those children but with no positive result. In fact the teasing increased after the complaint".
>
> *woman 28, with moving difficulty from cerebral palsy. 018*

☹ **exclusion from school because of difficulties:** A few people in each city had been excluded from school because of their difficulties:

> "He can't say a word but can explain with the help of signs. Though he can't hear, when an aeroplane flies over he looks up to the sky. He has even worked in a garage for last 2 months. He goes to his workplace alone. He carefully crosses the road, also goes to local shops. He leaves for work at 7am and comes back home at 5pm. He wants to study but teachers don't want to take him in the local school".
>
> *father of boy, 8, with speech and hearing difficulty. 146*

iv) Structural barriers:

☹ **children in mainstream school without any appropriate support**: Some persons with speech and hearing difficulties were in mainstream school without any additional support. Their experiences varied; some appeared to be managing fairly well, others were not:

> "the teacher complains to me about my speaking problem. She hits me everyday".
>
> *boy, 16, with speech difficulty. FGD2.1*

☹ **unacceptable behaviour:** A few children with learning difficulties had apparently discontinued because of their unacceptable behaviour. Mainstream schools did not have any means of addressing behavioural difficulties and thus teachers, or parents in response to teachers' complaints, had excluded the children from school. Inputs for modifying unacceptable behaviour were unavailable at home, and so caused problems there and in the community.

Question 2.3.3: what are the barriers to special schools?

The largest barrier to special school attendance is the small availability of special school places. Beyond this, some barriers to mainstream schools also apply to special schools. For example, some children in special school dropped out for no obvious reason other than a lack of motivation on the part of parents, teachers, and the child.

i) Structural ii) economic and iii) environmental barriers:

☹ **distance and cost:** The nature of special schools' catchment means that most children have to travel some distance from home. This puts additional stresses on school attendance, particularly for children who are less able to walk long distances, use public transport, or travel unaccompanied. The cost in time and money of such travel is also a barrier to attendance, particularly for poor people.

☹ **cost**: In all three cities, some parents reported that they had sought admission to special schools for their child but had been put off by the fees charged.

ii) Attitudinal barriers:

☹ **unhappiness with quality and type of education offered:**

> "She used to go to a local special school, but they didn't take proper care of her, so she has discontinued". *mother of woman, 18, with learning and speaking difficulty. 054*

Several parents of people with communication difficulties reported that they had tried special school but had not been satisfied with the education offered. They thought that their child was 'less disabled' than others there. A couple of parents of children with learning difficulties had removed their children as they felt that they were learning unacceptable behaviour from other children, or losing their self help skills.

☹ **children excluded because of behavioural difficulties.**

☹ **negative social impact of segregation:** some parents expressed concern that special school would make their child segregated from the mainstream of life:

> "She is a 'slow learner'. I feel very bad that my child who was in a normal atmosphere has now come to a special school... they should have extended help to her in such a way that she could have got back into the mainstream.... this place caters more for the child with severe problems...my daughter is borderline, but it has made her into a special child instead of a normal child". *mother of woman with learning difficulty, 21, Bangalore*

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answer: The most important barriers to special school attendance relate to their limited coverage, and the distance from home of such centre-based institutions.

2.4 NEEDS AND EXPERIENCES OF MEDICAL REHABILITATION

Medical rehabilitation was not the first priority need expressed by persons with disabilities and their families in low income communities. However, because of the absence of other services to address priority needs for income and education, for many people, their only experience of service use in relation to their difficulty was in the medical domain. Most of the persons with disabilities and their families had, at some time in their lives, felt a need for medical rehabilitation, although needs typically changed with age:

- The parents of young children with disabilities often focused on a possible cure.
- This was followed by an expressed need for practical information about their child's impairment, and what their expectations should be in terms of ability and therapy.
- Then parents wanted inputs which would increase their child's functional abilities, to participate more in mainstream life.

These needs were generally expressed by parents during their child's first 10 years of life. After this, expressed needs for medical services declined. Some older people and their families expressed ongoing needs, such as for inputs for mobility, and for medical management of epilepsy, but these were rarely prioritised in discussion. They had generally reached a point where they had given up hoping for a cure, and had also reached an understanding of what types of medical rehabilitation are available to people from low income urban communities. After this point in life, most expressed non-medical needs.

Many persons with multiple disabilities and carers had spent their entire time in each other's company, with little external interaction. It was unsurprising that both need additional sympathetic social interaction. For some mothers who looked after people with multiple difficulties, the study fieldworker was the only person whom they had spoken to about their needs for a long time. Even those with other family members did not necessarily get any support from them. In fact, the presence of a person with disability might cause additional family problems. There was an obvious need for emotional support and counselling for some persons with disabilities who felt that they were a burden on their family, as well as carers who were depressed or lonely. The mother of a young woman with moving and learning difficulties broke down in tears when she described her circumstances:

> "She sits down in the room the whole day. She is totally dependant upon me, she uses the bed pan and I have to help her to move about. I bathe her in the kitchen by carrying her, she is too heavy and difficult for me to carry outside. The other tenants avoid mixing with us because they don't want to see her. I can't leave the house because of her. I get very lonely. I have four daughters and two sons. My sons live in the same house as us but don't have good relations with me".
>
> *mother of woman, 23, with moving difficulty and learning difficulty. 024*

answer: needs for medical rehabilitation can be summarised as i) appropriate information, ii) improved function, and iii) emotional and social support.

Question 2.4.1: what do medical services offer persons with disabilities?

At first contact with medical services, they were usually offered assessment and diagnosis. Beyond this, what medical services offer is dependent on difficulty group.

moving difficulties: services address people's impairments through exercises to prevent further deformity; surgery; and the provision of aids and appliances to improve mobility. In the past, other therapies such as electric currents to stimulate affected limbs has been part of service provision in government hospitals.

speech and hearing difficulties: assessment and possible referral for a hearing aid.

epilepsy: investigation and prescription of anti-convulsants.

seeing difficulties: assessment, surgery if appropriate.

learning difficulties: diagnosis.

Question 2.4.2: what are persons with disabilities' experiences of medical rehabilitation?

Persons with disabilities were asked what services they had used in relation to their difficulty. This question was specific to services for persons with disabilities; thus, mainstream schools are not included here. The coverage of rehabilitation services was as follows:

Table 14: Proportions of persons with disabilities using different types of rehabilitation services

city	*% of sampled person with disabilities using service type*			
	medical rehabilitation	***special education***	***special employment***	***welfare services***
Calcutta	92	7	6	29

Bangalore	86	8	1	16
Visakhapatnam	87	18	2	31

Overall, 88% of persons with disabilities interviewed had used medical rehabilitation services in relation their difficulty. Medical services used for other reasons (i.e. not related to an individual's difficulty) are not included here. It has been suggested that much of this service use, such as attending government hospital OPDs and private doctors, was not of 'rehabilitation services'; rather it was 'medical intervention', and thus does not belong in this examination of medical rehabilitation services. However, for the purposes of this study of the service use of persons with disabilities from low income communities, all services which persons with disabilities and families described as being used 'in relation their difficulty' are included. It has also been suggested that 'rehabilitation' only begins after such medical intervention. However, in this study, such 'medical intervention' was, for many persons with disabilities, their only contact with services used in relation to their difficulty. In rehabilitation terms, any such service use is at least a potential opportunity for communication of appropriate information.

Of the difficulty groups, the largest group of people not consulting a medical rehabilitation service was that of speech and hearing difficulty. Most of the persons with disabilities interviewed had sought service in government hospitals. Many people had only ever used medical services, and hospitals were the only place known in which to seek services. This is in spite of the fact that the priority needs described are not medical. Of all the persons with disabilities encountered, less than 5% had used NGO organisations providing services for disabled people (note that this refers to the 587 persons with disabilities in the community studies' use of all NGO services in their home city, and does not refer only to use of the NGO services evaluated in the UCBR Project).

Experiences of medical rehabilitation vary according to the type and degree of difficulty, but there are common themes. The pattern of contact with medical rehabilitation over the life span of a person with disability was generally an intensive pursuit of a cure, followed by increasing frustration while trying to use available rehabilitation services, before ending service seeking altogether. This was usually because of lost faith in service options, rather than the logical end point of a time-limited rehabilitation process.

answer: medical rehabilitation services had been used by 88% of those interviewed. Most service use took place at government hospitals, typically early in a person's life. Less than 5% had used NGO medical rehabilitation services.

Question 2.4.3: Do medical services meet expressed needs?

i) Meeting the need for appropriate information: Parents' expressed need for a cure for their child's impairment cannot be addressed by medical rehabilitation services. However, parents' disappointment on realising this was exacerbated by the fact that the information about their child's impairment given to them by medical service providers was unsatisfactory. Parents reported that they had been confused about their child's impairment and difficulty, and particularly what they could expect in the future. Medical practitioners had given conflicting advice, and confusing inputs. A common example was that doctors had said that 'nothing can be done', and then prescribed medicines, typically tonics and vitamins. In the short term, frustrated parents were likely to seek alternative medical opinions. In the long term, many abandoned their attempts to seek rehabilitation inputs, medical or otherwise. Parents' frustration was vivid:

> "We hear that government hospitals provide wheelchairs but we don't get them. We have visited NRS Hospital several times but they have only asked us to do exercises and haven't given us any medicines. At one instance I was about to smack a doctor but I stopped myself, thinking that they may take me to court. I swore and shouted 'If you

> know that you can't do anything, tell us, don't just suggest exercises. Then we can go somewhere else for treatment'". *mother of girl, 8, with moving difficulty. FGD.2 Calcutta*

In some cases, information was so limited that parents considered that diagnosis was the end of the medical rehabilitation process. A lack of information was also experienced by some of the seven people with epilepsy interviewed. Although they had been prescribed anti-convulsants, at least two had stopped taking them and had increasingly frequent fits. They had not received adequate information about fit management; their families had not had information about what to do during a fit. In summary, there is very little evidence to suggest that medical rehabilitation practitioners give appropriate information to poor people.

ii) Meeting the need for improving functional ability: Improving function, such as mobility and hearing, is the key aim of much of the medical rehabilitation. This is apparent from the importance placed on interventions such as physical management exercises, surgery and provision of aids and appliances. It is impossible in the current study to state categorically what the impact of these interventions is on mobility and avoidance of further impairment.

a) **Physical management exercises**: Physical management exercises had been advised for virtually all of those with polio who had sought medical rehabilitation services and for some with other moving difficulties such as cerebral palsy. Usually, parents had been told to bring their child regularly to a centre to have physical management exercises performed by a therapist. Descriptions of exercises indicate that most are passive movements and exercises were not related to every day activities. A few people had been shown exercises to perform at home; few reported that they had continued doing these for any sustained period and the majority had never done exercises at home. The lack of adherence to physical management exercises suggests that their current provision by medical rehabilitation services does not meet the needs of persons with disabilities and parents.

b) **Surgical Interventions**: many of those with moving difficulties from polio reported that they had had corrective surgery, particularly in Visakhapatnam. Again, it is not possible to comment on the effectiveness of surgery with the small number of respondents. Some had obviously benefited from surgery, but the majority of those with moving difficulties who had had surgery recounted that they had undergone surgery with no positive impact on mobility. Others had been advised to have surgery but had refused to comply, fearing that the operation would go wrong, or had received insufficient information about the aims and extent of surgery:

> "We went to the hospital. They said an operation is necessary and also gave electric shock treatment and massage, but I got scared hearing about the operation because I thought that they will amputate his leg, so we stopped going there".
>
> *mother of boy, 4, with moving difficulty from polio. 143*

c) **Provision of aids and appliances**: The supply of aids and appliances constitutes a large part of existing rehabilitation service provision. Callipers, crutches, and wheelchairs had been supplied to many of those with moving difficulties in the three cities. These came from a variety of sources, but the majority had been supplied through hospitals. During the three community studies, it was striking that very few of the persons with disabilities were using them at the time of interview. The aids most commonly seen in use were crutches. Callipers were almost never seen in use. Most of the people who had got aids were now managing their mobility without them, by anything from crawling to hand-to-knee walking, although many reported in qualitative interviews that they had been issued with callipers, and wheelchairs. Across the community study, negative accounts of aids and appliances outweighed positive. In all three cities, some of the aids supplied had never been used as they had never been appropriate to the individual's needs. Others had been used briefly, but had become inappropriate:

> "I got a wheel chair from a club in 1992... now the wheelchair is of no use; look [*points*] we dry clothes on it now. I can't control the back of the wheel chair because I have hardly any strength in my hand, so I don't use it".
>
> *man, 20, with progressive moving difficulty. 022*

> "I was given an artificial limb 7 or 8 years back from Medical College, but I cannot use it because I cannot strap it to my leg since I don't have enough strength in my hands - when I was 7 years old, I fell into a drain and broke my elbow - we didn't plaster it. 2½ years back my right wrist was fractured and was not plastered. When I ask my son to help me to put on the artificial leg, he doesn't do so and tells me that it is my headache".
>
> *woman, 50, with moving difficulty. 120*

Other aids were rejected as they broke, or were not properly adjusted and uncomfortable:

> "From National Institute for the Orthopaedically Handicapped I received a free calliper but I couldn't use it for more than 1½ month because of pain in my leg... I also received a wheel chair and crutch from Congress Party, but I don't use it because I want to be self sufficient... I don't really need them anyway. But I lend the crutch and wheel chair to people who need it". *man, 24, with moving difficulty. Calcutta 133*

Qualitative information indicates that most aids are not regarded as useful enough for people to be motivated to try and get them replaced.

For persons with severe and multiple impairments, appropriate aids such as seating aids had rarely been discussed or supplied. Most advice regarding such aids was stereotyped and given with little thought to the circumstances of poor household.

> "...they said do physiotherapy and even asked us to make her stand in a water tank filled with sand... from where are we going to get a water tank? We hardly have enough space in this room anyway... they asked us to make special shoes as well... what is the use of these things?... she crawls around, and either sits or sleeps for the whole day. She spends most of the time with me and she cannot say when she wants to shit, and does so in her panties... what can we do about that?".
>
> *grandmother of girl, 4, with moving difficulties. Calcutta 147*

The experience of hearing aids is similar. Beyond treatment for ear infection, the only service offered to this group is assessment and a hearing aid. Hearing aids are unsuitable for those who have total hearing loss, yet some of this group had been advised to get an aid. Some aids issued did not work. Obviously, in both cases, a person with disability's need for functional improvement is not met. Others, whose hearing could be functionally improved by a hearing aid, were not having their needs maximally met by the aid as no appropriate educational support was available. Such support is only available in some special schools, and the coverage of these is small. Thus even if all people had the type of impairment which a hearing aid could help, their need for improved communication is unlikely to be maximally fulfilled as the coverage of educational support is so limited. Moreover, medical rehabilitation services do not integrate with educational services.

If aids and appliances are supplied free by government hospitals but remain unused, they constitute an expenditure that is neither functional or cost effective. This inappropriate expenditure was shared by some low income households which had paid for their unused aids and appliances. Cost is also a barrier to the use of hearing aids. Although they are available free, several of those interviewed had been assessed and advised to buy a hearing aid, sometimes as government supplies were unavailable. Considerable costs are also associated with maintaining an aid:

> "About 7 years ago I had a buzzing sound in the ears and visited NRS hospital... the doctors sent me to the Directorate of Social Welfare for hearing aids, who gave us the address of a shop and they supplied a free aid, although I had to wait for about 6 months or 1 year. Previously I used to work in a household as a maid and earned Rs.125. Now I have left the job as I can't follow what people are saying. The hearing aid was free at the start, even though it took a long time to come, but over the time it has cost me lots of money. I have to change the wire of the hearing aid every 3 to 6 months which costs Rs.50... and the battery every 2 months depending upon its use, this costs Rs.4.75 per battery. Presently the volume control switch is not working properly... to repair it one of the shopkeepers said that the parts required will cost Rs.350 which I can't presently afford. I am having problems... even with it on a person has to speak loudly so that I can hear, and I can't hear at all without it. These days, I sit quietly and go to bed very early. I prefer not to talk to people in the neighbourhood or have them visit me now because if someone say something to me I may not follow and say something which doesn't have any relevance... people also try to avoid me. In fact some people make fun of me because I give them irrelevant answers". *woman, 65, with hearing difficulty. 038*

There were also people who had never wanted aids and appliances. Some were rejected as they or their families did not like them. Callipers were described by some respondents as ugly, and as bringing more attention to that person's difficulty. Similarly, some children did not use their hearing aids as they were teased by other children.

Overall, the effectiveness of the provision of aids and appliances to address needs for improvement of functional abilities is in doubt. Aids and appliances constitute a major part of the medical rehabilitation services in the three cities, and yet it appears that many of the aids supplied have little functional impact. This implies that their supply is not effective, which is a concern given their central place in rehabilitation policy and the fact that they constitute a considerable cost to the Ministry of Welfare, to rehabilitation organisations, and to persons with disabilities themselves. Finally, the priority needs of persons with disabilities after the age of 10 years were largely centred on education and work. Medical services, which are the most commonly used services for persons with disabilities in the three cities, do not address these, and rarely integrate with service providers that do.

answer: qualitative data indicates that persons with disabilities experiences of medical rehabilitation are characterised by a failure to meet their needs for appropriate information, or for improved functional ability. In each of the cities, a need for monitoring and evaluation of intervention outcomes was apparent.

Question 2.4.4: What are persons with severe and multiple impairments' experiences of medical rehabilitation?

Common themes in the experiences of medical rehabilitation of people with severe and multiple impairments and their families are summarised below. They evolve and change as the child gets older:

- Parents notice baby's difficulties at an early stage and seek medical help.
- Doctor tells them "wait and your child would improve" or "nothing can be done":
- Parents pursue cure from several places.
- Different doctors prescribe 'medicines' but there is no improvement.
- Mother continues service seeking, and is advised to bring her child regularly to central service for exercises to be performed, which she initially tries to do.
- Mother finds travelling to centre-based service too difficult as child gets heavier and she is less able to carry him. Also she may have other children to look after.
- Mother becomes disenchanted with service seeking as there is no appropriate help for skills training, no emotional support, and she can see no improvement from her efforts.

- Child gets older and needs change: there is an increasing need for self management skills, but mother has lost faith in centre-based services and so gives up seeking medical rehabilitation. There is no help in skills training or educational support available in their own community.
- Neighbours suggest that she put her child in a hostel but mother does not want this; she wants to do the best for her child at home, by helping her to become more independent. She wants her child and the whole family to have a secure future together.

Most of the families of persons with multiple difficulties had undergone some of these experiences as their child got older. Despite pursuit of medical rehabilitation, most real needs remained unaddressed. Some had stopped service seeking at a stage when their child was still young enough to make the delays in development of self management skills of little concern. They were looked after as if babies and parents reported that they had managed their child's needs relatively easily. Difficulties developed when the person was still dependent on their mother when fully grown.

answer: persons with severe and multiple impairments' experiences of medical interventions are similar in type, but more extreme than other persons with disabilities. Needs for appropriate information and functional improvement are not met, particularly as age increases. For most, all support comes from their own families.

Question 2.4.5: What are the barriers to medical rehabilitation services?

The study found that not only do medical rehabilitation services meet few of the real needs of persons with disabilities, services are also characterised by barriers to their use, particularly for urban poor people. The most common barriers relate to the fact that all of the services described were organised on a centre-based model, thus are inevitably a considerable distance away from most low income communities. The barriers to medical services are described in detail below. This is not to over play the importance of medical rehabilitation, but to indicate the range of barriers associated with all centre based services.

i) Structural barriers, and ii) associated economic barriers:

☹ **time and the indirect costs of frequent service use:** People with moving difficulties were advised to attend hospitals regularly for physical management exercises. To many parents, frequent visits were impossible. One-off service use for curative purposes was regarded as significantly different from regular service attendance. Hospital service hours are during the working day; parents had to work or do household work during this time. Taking regular time off was not possible; the self employed could not afford to miss work, and few employers of poor people allow such regular time off. Interrupting household work had effects on the rest of the family. In all three cities, mothers described having to leave home early in the morning to attend hospital services, particularly to allow for delays in public transport (late buses, and not being able to board crowded buses with their child with disability). This meant that they did not cook for their other children who, without food, would not go to school. The cost and practical difficulties associated with transport were also significant barriers:

> "Then I took her to hospital where they gave her powdered milk and showed exercises; she continued attending there until she was 5 or 6 years old. We went to a Spastics Society 2 or 3 times, but we stopped as the distance was too great, and the transport was difficult. It was too expensive, and my daughter had grown heavy by then".
>
> *mother of girl, 13, with severe moving difficulties*

For many poor people, their first service use was also their last, irrespective of service providers' advice to attend regularly.

Time was also a barrier to the effectiveness of the few services which passed on skills for physical management in the home. Shortage of time combined with a lack of understanding of why the exercises were to be performed, and a dissatisfaction, or boredom, with exercises which did not lead to any obvious improvement. Time, particularly related to serial interventions, was also a barrier to compliance with advice for surgical procedures. Some people with moving difficulties described having undergone serial operations. Surgery, whether beneficial or not, can be a time consuming and traumatic procedure.

☹ **direct costs of service use:** In each of the three cities, a number of persons with disabilities had consulted a private doctor about their difficulties, which indicates that direct expenses are incurred in service seeking. Surgical intervention was also costly to the families of children with disabilities. Even if the operation in a public hospital is free, the costs of admission and lying in constitute a considerable burden to families. Where public services are not available, use of private medical facilities exacerbate costs. Anticipated costs of interventions are a barrier to service use for low income households. When surgery cannot be avoided, these costs indicate a clear link between disability and increasing poverty:

> "The doctor again asked to bring him to PG hospital for plaster once again. We went to a private hospital instead, we couldn't bear to do it to him again, but the doctor asked for Rs.10,000 for the operation which we can't afford, so we dropped the idea. He crawls around in the house". *grandmother of boy, 11, with moving difficulty. Calcutta 193*
>
> "In 1993 I fell down from a tree. The next day I was brought to the city by train and taken to the Marwari Hospital - there was no bed there so we went to a private hospital where they wanted Rs. 2,200 for admission. We didn't have the required amount and so we went to Medical College where there was house staff strike. Then they took me to a nursing home and they admitted me for 1 day after which time my father borrowed the necessary money and took me back to the private hospital where they operated on my spine. There I was admitted for 90 days, the cost of which was about Rs.28,000. A harrington rod was fitted in the spine and the doctor told me to come and get it removed after about 1½ year. This would entail me getting admitted again for 1 month and would cost about Rs.15,000. We could not afford this amount and so could not get readmitted for the removal of the rod, so it is still there in my back. I now have lost the use of both legs and have no rectum and bladder control and also no strength in the hip".
> *man, 37, moving difficulty as result of spinal injury. 164*

The direct costs of medical services were also a barrier to investigations and control of epilepsy.

Question 2.4.6: is the use of medical rehabilitation services sustained?

answer: Few of the persons with disabilities had reached the end point of logical, time limited medical rehabilitation. Rather, they had abandoned medical rehabilitation inputs as the services did not address their changing needs, and because the barriers to service use were too great.

2.5 NEED FOR INCLUSION IN URBAN COMMUNITY DEVELOPMENT

The need for work, and education were expressed as needs in relation to participation in community life. This was the issue behind other needs; inclusion and access to all urban development, and more acceptance and respect in the community at large.

2.5.* Inclusion of persons with disabilities in municipal services

The study did not specifically examine the use of municipal services in the community studies. The study did quantify the participation of persons with disabilities in schools in the cities (section *). Mainstream and special schools were distinguished but the various types of mainstream school were not. Therefore, data for mainstream education can be assumed to include Municipal, Government, and some private schools. Experiences of other municipal services, such as public health infrastructure, arose in qualitative data such as in-depth interviews and FGDs (see section *.*).

One of the organisations included in the evaluation of a range of eight existing services for persons with disabilities was an attempt to integrate persons with disabilities into general metropolitan/municipal services (organisation * in Table 1, page *). This organisation started specific activities for the inclusion of persons with disabilities in one health administration unit (HAU) of a Metropolitan/Municipal structure. This involved 72 people in a population of 35,000 (approximately 0.02%) so did not include all persons with disabilities, and was not a random sample of all persons with disabilities, and included a wide range of difficulty and age groups. The persons with disabilities were identified by community health workers amongst their beneficiary population. The 72 persons with disabilities identified represent about one tenth of the number that there might be expected to be in this population. This suggests that municipal health workers were limited in their ability to identify persons with disabilities.

As in the community study, the main specific needs expressed by persons with disabilities and their families were for income and education. Most had already sought services from medical institutions, mostly government hospitals but also local rehabilitation NGOs. Some expressed further medical needs.

In education there had been limited informal inclusion in corporation schools, mainly for those with moving difficulties, but there was no support for specific needs of children with other difficulties. A few children had dropped out of school or been requested to leave because of their lack of progress. One 15 year old with partial seeing difficulties had been excluded from a corporation school. He was placed in a local non-formal school run by a local club, but this stopped when this non-formal school closed. One young woman also expressed a need for education, and as a consequence of the support of the fieldworkers in liaising with her family and teaching staff, she was included in a corporation non-formal school. However, she had difficulty maintaining regular attendance because of lack of backup and ill-health.

There was an expressed need for vocational training for young unemployed adults with disabilities. A 'camp' for persons with disabilities to meet local community development staff was arranged, and five persons with disabilities were identified for inclusion in existing mainstream vocational training. Of the five who were selected, three were irregular or dropped out of training. Two dropped out because of a lack of adequate back up services such as transport to the training, and one because she had found job as a household maid. Of the two that completed training (in television repair), one stated that in order to start to earn money he would need to get a higher level of training and also access to capital with which to start a business. One young woman had already completed 3 different vocational training courses but was yet to find work. This is a common problem in all vocational training and not specific to persons with disabilities.

Finally,most of the 72 had already consulted medical services, mainly in government hospitals, and a few NGO medical rehabilitation services. The municipal/metropolitan structure referred them to further medical rehabilitation services. Without this specific support from the Municipal structure (such as making of group appointments for assessment and provision of transport for such visits) persons with disabilities reported that they had experienced the same difficulties as reported in the three community studies.

Question 2.5.1: is access to urban infrastructure difficult for persons with disabilities?

As well as barriers to work and education, persons with disabilities described their exclusion from other things such as sanitation, water supply, public buildings, and public transport. They rarely voiced the perception that these things should be changed or planned to make them more accessible. This could indicate that such access is less prioritised than other needs. However, it may indicate that poor people are not empowered to voice opinions about the form which urban infrastructure takes. Thus, persons with disabilities are excluded from services as their specific needs are not addressed.

answer: access to urban infrastructure is difficult for persons with disabilities, but this was less expressed as a priority need than income and education.

Question 2.5.2: what are the barriers to access?

Persons with disabilities described barriers to their use of various facilities. For example, pumps are too far or high, roads too rough with nowhere to cross, and public buildings have steps. Some of these barriers are experienced by other urban residents who do not have impairments. The example of access to toilets is salient to illustrate the marginalisation of the needs of persons with disabilities in urban infrastructure development.

The public health function of sanitation services demands safe toilets for all. If persons with disabilities are excluded from safe sanitation they may contribute to the transmission of disease in the household and community. Section 2.4.4 described difficulties in safe toiletting for those without toiletting skills who depend on family members to assist them in toiletting and washing afterwards. Other persons with disabilities described difficulties in using the sanitation facilities available in their community. Another link between sanitation and impairment was defecation in dangerous surroundings. Several persons with disabilities interviewed had been involved in accidents while defecating; one had been hit by a train; another had fallen into a drain into which she was defecating. Both had resulted in permanent impairment.

☹ **difficult physical access to toilet**: Defecation in the open is common for small children, some of whom are told not to use community toilets in case they fall in. It is not socially acceptable or safe for adults in densely populated areas. Some persons with moving difficulties described being unable to use common toilet facilities, both those built by householders and by municipal authorities. Toilets were inadequate for the community at large and even less suited for use by persons with disabilities:

> "There is one toilet shared by the five families nearby, but to reach it you have to go through an area where everyone dumps their garbage and children in the neighbourhood defecate all over that area, and she can only shuffle on her bottom through it...therefore she goes to toilet on the veranda where she sits and her sister wipes the floor with a piece of paper and throws it in the dumping area near the pond".
>
> *mother of woman, 20, with moving difficulty, 111*

> "She roams about the area on four limbs and sometimes uses her *chappals* on her hands. This toilet is shared by 25 families. She can't use it as it is very slippery in there and she may fall. Moreover it is difficult for her to lift herself onto the toilet seat, so she prefers to go on the canal side. In the rainy season, she goes there all alone since I may fall sick if I

> am helping her and get drenched in the rains, and if I get sick all the younger children may fall sick". *mother of girl, 7, with moving difficulties. 118*

☹ **no water source close to toilet:** Those who could not move to the toilet and carry water with them were dependent on someone to help them carry the water. When this was not possible they often chose to go to toilet close to a water source instead, such as on the bank of a *nullah*.

answer: barriers include toilets which cannot be accessed by those with difficulty moving, and a lack of water near toilets.

2.6 NEED FOR ACCEPTANCE IN THE COMMUNITY

Question 2.6.1: what are persons with disabilities' experiences of family and community attitudes?

Persons with disabilities who were participating in mainstream life, such as attending school or working were reportedly treated as any other family and community member. It appeared that active participation in the mainstream of life had the greatest impact in creating positive community attitudes.

Some of those with greater difficulties, and less immersed in the life of the community, were more likely to be treated negatively by their family and the community at large.

> "Our mother says 'you just sit and eat and don't help in the family income'. He doesn't want to sell fruits with his father and brothers or sort plastic with me. He hates himself. He roams around... he is totally useless... our parents thought that being the eldest brother he will take responsibility for the family. But instead he demands good food like meat". *sister of man, 16 with moving difficulty and indistinct speech. FGD2.2*

However, such feelings about young men who do not do their share of work are not restricted to persons with disabilities. Some extended families all treated their disabled family member with love, respect, and shared responsibility for providing support when necessary. In other families, care for a person with disability was the responsibility of one member, typically the mother. Some families used names for the disabled person that were defined by their difficulty. The abuse intended in such names varied, but persons with disabilities generally resented such names. This did not always deter others:

	Calcutta FGD2.2
Fieldworker:	We have heard your sister call you '*khora' [cripple]*. How do you feel about it?
Boy, 15, with moving difficulty:	I don't like it but what can I do?
Boy's sister:	Children and even adults tease him and pull his trousers, and spit on him. But as *khora* doesn't have any strength in his leg he falls down after a few steps so can't chase them.

An important bridge between family and community life is attendance at social functions such as marriage parties. Most persons with moving difficulties resulting from polio reported that they attend all functions with their families. A few young adults chose not to go as they felt self conscious. Many older persons with severe and multiple impairments were excluded from functions by their families. For some this was because they would have to be carried; others were excluded because they did not have toilet skills, but those with multiple difficulties, and people with strange behaviour were widely excluded because "people did not want to look at them".

As with family attitudes, respondents described a continuum of experiences in the community, from descriptions of special efforts made by neighbours to help them; persons with disabilities who are treated like any other citizen; to persons with disabilities exposed to extreme verbal and physical abuse. This mixture is illustrated by the following description:

> "The neighbours tease me, I become very angry. Sometimes in anger I try to hit the person who teases me but I can't do it because I don't have control over my movements. I have a few very good and close friends who carry me to the cinema. I don't have a good relation with my siblings. The members of the family and the neighbours call me '*Khora*'".
> *boy, 15 with moving difficulty. 152*

Negative attitudes vary. Some persons with disabilities were physically attacked:

> "Due to his odd behaviour he also gets beaten by people and so we have to try and protect him.. to prevent him loitering about we have to tie him up with rope".
> *father of man, 23, with learning difficulty, epilepsy and strange behaviour. 150*

More were subject to name calling or questioned insensitively about their impairment. A common theme reported by children with disabilities and their families was that neighbours were generally supportive and positive, but would resort to abuse about the person's difficulty in times of conflict. Strangers were generally more abusive.

A number of persons with disabilities described the great support that they had got from their community. This was of two types. Friends might be supportive on an ongoing basis, like family carers. This was more common for people who had become disabled by accidents and so had friends from before this occurred:

> "At one time I found a lady whom I intended to marry but due to my financial instability I couldn't do so. Seeing this, my friends came forward and helped me to open a shop near my house. I sell soaps, hair oils, cosmetics, and cigarettes. I am quite popular in the locality and have 100% co-operation from people here. Everybody loves me. After that I got married to that lady and now we have a 2½ year old son".
> *man, 38, with moving difficulty, 021*

Community organisations, such as youth clubs, and political parties, tended to act with one-off efforts. Several people throughout the communities sampled had received aids and appliances from local community clubs, and also Lions and Rotary clubs further afield. One young man was given financial help to pay off loans taken for medical treatment by a local youth club which raised contributions from local businesses.

answer: experiences of family and community life and attitudes vary. Many positive examples and many negative experiences were discussed in each of the three cities. Virtually all persons with disabilities interviewed received support from their families.

Question 2.6.2: do persons with disabilities get married?

Discussions of marriage virtually all referred to arranged marriage. Some persons with disabilities were married; some families planned that they would get married; other were not expected to get married. In Visakhapatnam and Bangalore, it was relatively common for young women with disabilities to marry their maternal uncle. Indeed, in one FGD in Bangalore, 6 of 10 women present had married their mother's brother.

answer: yes, some persons with disabilities do get married.

Question 2.6.3: what barriers are there to persons with disabilities getting married?

The key determinants of whether marriage would be possible for persons with disabilities appear to be the following:

☹ **the nature of an individual's difficulties**. Those with less severe moving difficulties were regarded as the most suitable for marriage, and those with learning difficulties and multiple difficulties the least. Many parents of persons with multiple difficulties had never considered that their child would marry. Other parents were trying to find a match but found that their daughters' impairment was a barrier to finding a willing man.

☹ **a man's inability to earn money and support himself and his wife**

☹ **a woman's inability to earn money, or to do household work.**

> 'Who will marry a lame girl like me? I won't be able to do any of the work'".
>
> *woman, 20, with moving difficulty, 111*

Marriage was also perceived as a transfer of domestic labour by the parents of men with disabilities. The possibility of a person with disability marrying another person with disability had been discussed in some households. Earning capability, household work, caring, and the marriage of other siblings 'in turn' were key issues.

answer: barriers relate to an individual's difficulty, and then to abilities to earn money, and for women, household work.

Question 2.6.4: what is marriage like for persons with disabilities?

A small number of the respondents were, or had been, married. All had married non-disabled people. Arranged marriages were the norm. From the limited number of examples, it seemed that the success of a marriage depended on personality, and hard work in earning money and keeping the household.

answer: as for any community, persons with disabilities' experiences of marriage include both good and bad.

*2.6.5 What is 'community'?

This study has reported the limitations of available services in terms of meeting the expressed needs of persons with disabilities and their families in low income communities. It has also described negative attitudes to persons with disabilities within their own households and own communities. Despite this, it has stated that, for many persons with disabilities, virtually the only support for their needs comes from their own 'community'. This begs the question: what is community?

In section * above, it was described that 'community' in the UCBR study means a geographical area in which a person with disability lives, as this was the unit of sampling used for the community studies.

Generalisation is difficult, but beyond this, the 'community' support for the needs of persons with disabilities apparent in the community studies means first and foremost family members, particularly mothers and female relatives who provide care and support for persons with disabilities. This ranges from emotional support for those with less severe difficulties, such as moving difficulties following polio; through to all-embracing physical support for those with severe and multiple impairments - everything from the purchase of food, to feeding.

This is followed by the extended family and household; and in some instances by neighbours in the immediate area with whom persons with disabilities have the most history of social contact..

In the wider community, support means opportunities for education for some persons with disabilities in local schools; and opportunities for skill learning and income generation in local community workshops and petty business.

The extent of such 'community' support varies from individual to individual. Support for persons with disabilities and their families appeared to most available when they were children, or when impairments were acquired later in life and thus individuals already had their own social networks to draw support from. Community attitudes, and related support, were most positive for persons with disabilities who were already participating most in the mainstream of community life, and for families who .

Support, understanding and the availability of community resources were least for adults with difficulties such as unacceptable behaviour, and a lack of daily living skills which distanced them from the mainstream of and as a result fuelled negative attitudes and limited support.

2.7 AGE AND DISABILITY

There are age dependent changes in needs and service use. Of all service provision, medical rehabilitation services are the most frequently used, but this typically took place during a child's first few years, when parents sought curative services and information. Some ended their service use at this time. Others persisted with medical rehabilitation, such as physical management and getting aids and appliances. With age, barriers relating to physical access to centre-based services also increased for those with moving difficulties.

Generally with age, needs evolved away from the medical and towards education and work. There is less provision of rehabilitation services to support these needs. Thus, persons with disabilities who could not use mainstream schools or secure mainstream work have no services support after their early contact with medical services.

The key informant process used to locate persons with disabilities virtually ignored those who were disabled and old. This short-fall makes conclusive statements about this group impossible.

answer: increasing age is accompanied by changing needs, and rapidly diminishing service provision.

2.8 GENDER AND DISABILITY

Possible differences in needs and experiences between female and male persons with disabilities were discussed in in-depth interviews and FGDs both in the community study and in the eight service evaluations, and analysed in the quantitative data. A number of patterns emerge, but with regard to qualitative data, a generalisable understanding of the relationship between gender and disability was unclear. For example, some parents stated that it was 'not worth' educating girls with disability, while other parents stressed that for girls with disability, education was their "only chance to gain independence". The relationship between gender and marriage for persons with disabilities are described in section *.* above.

Gender specific experiences of persons with disabilities largely reflect the gender specific experiences of the population at large. In Calcutta and Visakhapatnam, the proportion of males attending school is significantly higher than the proportion of females (Calcutta; 54% males, 39% female; Chi^2=4.088; df=1; p=0.04319. In Visakhapatnam 66% of males and 48% of females Chi^2= 6.98781; df=1; p=0.0082). In Bangalore 66% of men and 58% of women had attended school but this difference was not statistically significant. This gender difference also occurs in the urban population in general (the average figure for all children in the 5 to 14 age group in urban West

Bengal, Karnataka and Andhra Pradesh combined can be estimated for 1987-88 as 74.8% and 69.6% for boys and girls respectively).

In Visakhapatnam and Calcutta women with disabilities were significantly less likely to be in paid work (Calcutta 43% males; 9% females. $Chi^2=15.4623$; df=1; p=0.00008: Visakhapatnam 56% males; 27% females: $Chi^2=8.51$ df=1 p=0.0035). Although some women were doing household work, they are even more economically reliant on other people, and have less control over their own lives. This difference is also reflected in training. Of those over 15 years old, 24% of men and just 9% of women had done any sort of training for work. Again, this is significant ($Chi^2=3.92$; df=1; p=0.047). As training mostly occurs in the workplace, this is unsurprising, but in terms of work skills for future employability, women with disabilities are significantly worse off.

There is no apparent difference in the relative use of medical rehabilitation services. Male and female respondents had used similar numbers and types of services.

Parents expressed a greater concern for the safety of disabled women and girls than men and boys. The added risks of assault and abuse were raised particularly for those with learning difficulties.

answer: females are less likely to attend school or do paid work than males. Risks in community life are perceived as greater for women and girls.

2.9 POVERTY AND DISABILITY

The literature review (section 1.2) referred to evidence that prevalence of impairments is higher in low socio-economic groups. The community study also described links between poverty and disability.

Firstly, families suggested that poverty can be a cause of an impairment. Qualitative data from the more marginal communities (such as squatted, canalside slums) indicated that provision of basic public health infrastructure and health information was less available there than in recognised slums. In such conditions, transmission of disease is known to be more intense. Infectious disease is a known cause of impairments, leading to disability. Although no prevalence figures are available for impairments, some respondents linked the lack of information about polio vaccination to the fact that their child had got polio. Other persons with disabilities linked their impairment with their inability to afford appropriate intervention.

Secondly, many barriers to rehabilitation services are poverty-specific. Whether barriers are a direct fee to a private doctor, a bus fare to a hospital, the wage lost while using a service, or a bribe to a service provider, cost is a bigger service barrier to poor people. Poor people stopped using services. Incurring the costs of rehabilitation services is an extra cost that other households in low income communities do not have. The limited data available suggests that persons with disabilities are less likely to go to school and are less likely to do paid work than the urban population in general. Carers of some persons with severe and multiple disabilities also reported that they are unable to do paid work. Therefore it appears that urban households in which there is a person with disability have additional costs to pay, and less opportunities to earn income than other urban households.

answer: it is known that prevalence of impairments is greater in low income groups. This study found that disability also contributes to poverty.

2.10 CONCLUSION OF THE COMMUNITY STUDIES

The priority needs of persons with disabilities expressed in the three community studies were for income, and education. For the majority, and with increasing age, medical needs were less prioritised.

Of the 294 persons with disabilities over the age of 15 interviewed in the community studies, 34% were doing paid work. These work opportunities had virtually all been found in their own community and had been accessed through local social contacts such as family, neighbours, and friends. Similarly, the majority of skills training for persons with disabilities was informal and had occurred in the workplace. Experience of vocational training was extremely limited, as was the experience of government support such as pensions, employment opportunities and loans. Of the 237 adults with disabilities interviewed, 28 (10.5%) had obtained a pension. One had secured a loan. One had a job through the government quota. Barriers to access include the poor attitudes of government employees and their demands for bribes to sanction application. Support for income generation by family members of persons with disabilities is not available.

43% of the persons with disabilities interviewed had never been to school. The percentage of all children in the 5 to 14 age group not going to school in urban West Bengal, Karnataka and Andhra Pradesh combined can be crudely estimated for 1987-88 as 28%. Persons with disabilities who had been to school had mainly attended mainstream schools. Barriers to mainstream schools included the negative attitudes of teachers, and in all three cities some children with learning difficulties and communication difficulties were in school without any appropriate support. However, across the three cities, the number of persons with disabilities who had been to mainstream schools out-numbered that for special schools by nearly five to one. The use of special schools was limited, and they were located far from most people's homes, so transport and other costs particularly excluded poor people.

Despite the prioritised need for income and education, virtually the only rehabilitation services experienced by persons with disabilities from low income communities are medical. 88% of those interviewed had used a medical service in relation to their difficulty, mostly government hospitals. Less than 5% had used NGO medical rehabilitation services. The study found that medical rehabilitation services did not meet even the medical rehabilitation needs of most persons with disabilities. For example, interventions for those with moving difficulties had a questionable impact on mobility. Many aids supplied were not used, and people were managing their own mobility without them. This prompts concern about the appropriateness of interventions and the cost effectiveness of services provided. A need for monitoring and evaluation of effectiveness is indicated.

Services for those with severe and multiple impairments were arranged for diagnosis, mobility, and prevention of further impairments. They did not address the day-to-day needs of persons with disabilities, particularly as they change across the life span. Services did not support learning of functional skills, which would help persons with disabilities gain more control over their lives, and allow family members to do other things. The only support available for most of those with severe and multiple impairments was from their own families.

To compound dissatisfaction with medical rehabilitation services, their means of delivery acted as a barrier to the urban poor. All of the medical rehabilitation services used were based in single centre institutions. Like special schools, this meant that they are a considerable distance from most communities. Distance contributed barriers relating to cost, time, and practical difficulties of transport (experienced by all groups of persons with disabilities), particularly when frequent service use was advised. Other significant barriers to centre based services were the cost of missed opportunities for paid work by persons with disabilities and family members. Beyond barriers related to the centre-based approach, additional barriers included the purchase costs of aids, payment for investigation, and the cost of hospital admittance. These costs either prevented service use or exacerbated the poverty of persons with disabilities in low income communities. Finally, descriptions of the treatment of persons with disabilities and families by medical rehabilitation institutions indicated that service delivery was unsympathetic and lacking in respect for poor people.

In conclusion, the real needs of persons with disabilities were largely unmet by rehabilitation services. The greatest support for their needs was found within their own families and in their home communities. Much of this support operated regardless of rehabilitation service provision which, in contrast, did not address real needs, was not located in low income urban communities, and was not organised to be accessible to poor people.

SECTION 3: SUMMARY OF EVALUATIONS OF SERVICE APPROACHES

The eight project partners offer a variety of approaches. Most combine several approaches within one service organisation. In the evaluation, the varied approaches within any one organisation were examined separately.

Organ-isation	Approaches to service provision
1.	**a. Centre based:** out patients department (OPD); special school; vocational training **b. Outreach**
2.	**a. Centre based:** OPD; special school; vocational training **b. Outreach**
3.	**a. Centre based:** special school; vocational training **b. Community based approach**
4.	**Home based approach,** with medical referral
5.	**Home based approach**, with embryonic integrated approach, with medical referral
6.	**Orientation for integrated education**, teacher training
7.	**Special education teacher training**, adult day centre, and insurance
8.	**Welfare approach**

Two of the partners (3 and 8 above) are organisations started by persons with disabilities. Two (1 and 7) originated as parents' organisations. Two (1 and 2) employ approaches based on a professional model of rehabilitation workers. Two of them were government and six were non government organisations. All except one (6) were included as partners in the UCBR Project because they claimed to be involved with the urban poor. In this review of the eight evaluations, each approach will be discussed against a frame of key issues. These are coverage, effectiveness, staff issues, participation, advocacy and cost.

3.1 COVERAGE

3.1.1 Coverage of the urban poor

All of the partner organisations describe themselves as being open to all persons with disabilities in the appropriate age or difficulty group, regardless of socio-economic status. The socio-economic coverage of each organisation was examined by comparing the distribution of socio-economic status of a random sample of service users with the distribution of socio-economic status of persons with disabilities in the related community study. Proxy indicators were used. Firstly, housing materials: a concrete roof indicates a pukka house, and mud walls a kutcha house. Secondly, the type of work done by the head of the household.

3.1.1.1 Centre based approaches: The centre based services evaluated were set up because there were no services at all for persons with disabilities in those cities. One was started by persons with disabilities themselves, the other by parents of children with disabilities, particularly those with severe and multiple impairments. These services have been pioneering in rehabilitation service development and been duplicated in other cities.

The coverage of two centre based services was heavily oriented towards upper socio-economic groups. For example, in one, 77% of the service users live in a pukka house, compared with less than 5% of the community study sample for the same city. The difference was also apparent using employment as an indicator. For the same organisation, 46% of service users came from households headed by a manual worker. The proportion in the relevant community study was 88%. Similar socio-economic coverage was experienced by another centre based service approach in a different city. 68% of service users live in pukka houses, compared with 15% of persons with disabilities in the community study. The difference is also striking if relative proportions of kutcha housing are compared. 4% of users live in kutcha households, compared with 38% of the community study. It is clear that centre based services serve a population with a distribution skewed towards upper income groups.

The community studies found that all centre-based services have barriers to their use which are greatest for poor people: particularly distance, access, time taken to use a distant service, cost of transport, cost of work time lost, and practical difficulties with transport. The extent of this barrier can be illustrated by the calculating the mean transport cost for OPD users per year. In one centre, the mean transport cost paid by OPD users was Rs.26.8 per visit. The mean number of visits per month was 1.7, and, per year, 20.4. The crude mean cost of transport per year can be calculated for each service user interviewed. The mean is Rs.579. Such barriers tend to increase as the age of persons with disabilities increases. The barriers particularly prevent poor people using centre based services, mean that poor people use services less frequently, and lead to poor people dropping out of service use.

The main mechanism by which centre based services address poverty-related barriers is to give progressive subsidies for service costs according to the socio-economic status of service users. Thus, many of those from low income households qualify for free services. However, poor people described the indirect costs barriers of centre based approaches as being more important than service fees. In short, waiving user fees does not do enough to enable poor people to use centre based services.

3.1.1.2 Centres with multiple approaches: Two of the organisations offer different service approaches, such as special school and OPD, in the same centre. These are organised on different frequencies of attendance: special school attendance is daily for six hours, whilst OPD attendance is a mean of 1.7 visits per month. In such a scenario, the daily school services include significantly fewer poor people than OPD services. For example, in one centre based organisation, the proportions of users living in pukka housing are 90% and 69% for school and OPD respectively (Chi^2= 8.55862, df=2, p=0.01). More poor people use centre based services which are arranged on less frequent attendance than those requiring daily attendance. This means that poor people get less service contact time. In one centre based organisation, over all service users, people coming from pukka households have a mean service contact of over 35 hours per month. In the same organisation, those coming from non-pukka households have an average contact time of under 7 hours per month. This difference between means is significant (f=8.6; df=1.0; p=0.01).

A condition of securing a place in special schools is a child's ability to attend every day. The barriers to centre based services mean that many poor people are effectively excluded from daily services. Thus, a situation emerges where there is one service which includes higher income groups and another includes lower income groups. Regardless of the comparative quality of inputs, the contact time for upper socio-economic groups is significantly greater. The inequity of this situation is further indicated when one considers;

- The annual cost per capita of special school service provision is more than 10 times the annual cost of OPD service provision (see section 3.6 below).
- The tendency for organisations to support special school users with their own bus service but offer no assistance to overcoming transport barriers by users of other services.
- The tendency to support the applications for government welfare services by special school users but not users of services such as OPD.
- The greater emotional support for children with disabilities and their families in special schools than OPD.
- The greater opportunities for participation by the families of children in special schools than other service users, in which to meet other service users and express needs.

3.1.1.3 Model centre based services, replication and coverage: The three centre based services describe themselves as "models" for replication elsewhere in India. They contend that such replication will increase the number of persons with disabilities included in rehabilitation services in India as a whole. They had developed training capacities through which to train people who want to start similar services elsewhere. However, those that come for training are mostly from higher socio-economic groups, and serve higher socio-economic groups. The evaluation found that it is extremely rare for people from low income communities to spontaneously come for training in order to start a service for the poor. Therefore, replication of such "models" will not increase service coverage for the urban poor.

Other approaches favoured higher socio-economic groups because they had specifically evolved to serve the interests of these groups. Both of the partners which had developed from parents' groups were made up of middle class parents. They understandably focused on the needs of persons with disabilities in their own income group and grew by attracting additional persons with disabilities and their families from this group. An example is the development of an insurance policy for persons with disabilities which provides for the cost of care needs when their family members have died. This idea has grown throughout India. However, the scheme is not advertised through media used by the urban poor, premium levels are not suitable for poor people and, indeed, neither is life insurance in general. Persons with disabilities and their parents of high socio-economic status do not automatically represent all persons with disabilities and their families.

3.1.1.4 Service approaches away from the centre: Barriers related to distance are lessened if services are located in the poorer communities and coverage of lower socio-economic groups increase. However, care must still be taken that service structures do not exclude poor people.

The outreach approach takes professional services to local centres. This should transfer the cost barrier of transport to the service provider. However, this assumes that outreach centres are placed within or close to low income communities. In total, 10 outreach centres in two cities were evaluated. Only one was found to be based within a low income community, and in community space. The other outreach centres were either in higher income areas, or associated with institutions and included few users from low income households. Indeed, these outreach centres had become mini centre-based institutions in their own right, with all of the associated barriers, particularly for poor people.

High expected frequency of service attendance was also a barrier to poor peoples' use of outreach centres. Parents were unable to stay with their child as initially demanded by the centre staff. Instead, parents tended to use the centre as day care as this allowed them to drop off their child and then do paid work. This proved to be one of the greatest strengths of the outreach approach and was a positive factor in the general socio-economic development of the households. However, others were unable to bring their child every day and dropped out.

Community-based and home-based approaches include a greater proportion of poor people. The relative socio-economic coverage of a centre and a community based approach is indicated in the following table:

Table 15: comparative coverage of socio-economic groups in a selected city

Sample	Proportion living in pukka housing (concrete walls and roof)	Proportion living in kutcha housing (mud walls)
1. Community study	15%	38%
2. Centre based approach	68%	4%
3. Community based approach	23%	17%

However, note that the proportion of the community based approach living in kutcha housing is less than half that found in the in the community studies. Obviously, the socio-economic coverage of community based approaches depends on the type of communities chosen for activities. Although this particular organisation served urban slums, these were by no means the poorest slums in the city. This was also the case for the municipally organised home based service approaches. For example, in municipal service, 27% of service users lived in mud walled kutcha housing, versus 41% of persons with disabilities in the community study. Again, the slums selected for municipal service delivery are older and more established than some of the slums randomly sampled in the community study. Municipal services work in recognised communities, and largely ignore persons with disabilities in the most marginal and impoverished areas, which were included in the community study samples.

The importance of distance and transport related barriers to poor people's use of centre based approaches was discussed above. A merit of both home-based and community-based approaches is that such barriers are avoided, either because service providers are local people, or because the transport costs are borne by the service. However, in both of the municipal home based approaches evaluated, the city government structures had difficulties in paying workers' transport costs, despite being included in service budgets. This may seem to be a small obstacle, but combined with low payment it was a major barrier recognised by community workers to their own ability to maximise service quality and coverage.

Summary: do service approaches cover the urban poor?

- **Service approaches which are located in or close to low income communities are the best at covering persons with disabilities amongst the urban poor.**
- **Centre based services produce the same barriers as the government hospitals described in the community study. These barriers exclude poor people and are a greater deterrent to service use than direct service costs.**
- **When centre-based approaches offer a range of services to persons with disabilities, service use tends to divide on socio-economic status rather than on service need. This further propagates inequity by giving high cost, high intensity service to more affluent persons with disabilities, and lower cost, low intensity services to the urban poor.**

3.1.2 Coverage of different difficulty groups

Most of the partner organisations had started with single-impairment orientations but are gradually expanding to include other difficulty groups. The barriers associated with centre based services made their use particularly difficult for those with mobility problems. These included people with moving difficulties, seeing difficulties, multiple and learning difficulties, who could not use public transport alone. In general, mobility related barriers increase as persons with disabilities got older and physically bigger.

Outreach centres which were not in the community had similar barriers. In the community, those with severe and multiple impairments might be excluded from outreach centres if they did not have toilet skills, or unacceptable behaviour.

In home based services, most workers were best able to meet the needs of those with less severe impairments, while doing little to address the needs of those with severe and multiple impairments. Community based services were similarly less good at including the needs of those with more severe impairments. The community-based approach evaluated was developed for children with moving difficulties. It is now trying to expand to serve all persons with disabilities but the intensity of need differs, and changes are required in the kind of service offered, training inputs for workers, and technical support.

3.1.3 Coverage of different age groups

The coverage of all of the organisations evaluated is oriented to lower age groups. For most, the extent of coverage of adults reflects the length of each organisation's life span. Most started working with young children, and some twenty years later these children, still service users, are now adults. One of the centre based services reported that it tries to 'wean' people away from the service and get the family to take charge. This was particularly the case for people with severe and multiple impairments and was related to increasing mobility difficulties and transport problems, but in some cases the result was an end to social, and other stimulation outside the household.

Only the embryonic integrated approach aims to include the needs of people who are both old and disabled.

3.1.4 Coverage and gender

There were more males than females in all community study samples and in the samples of users of all organisations evaluated. This difference is found in the Indian urban population in general and in surveys of persons with disabilities.

In counselling activities, and where service providers perform physical management exercises on persons with disabilities, some concerns were raised about the interaction of male workers and women with disabilities. In most of the organisations, this was avoided as there were sufficient female workers. When this is not the case, appropriate recruitment and worker management can avoid problems. For physical management, creative approaches which maximise the active participation of persons with disabilities and their families should limit such culturally sensitive contact and improve the effectiveness of intervention.

Some of the vocational training available had a very high ratio of males to females. This was because of the trades offered in relation to work opportunities of men and women, and because in one case application was explicitly for young men. All of the community studies found that men and women need paid work, so vocational training should be arranged to meet the needs of both.

3.2 EFFECTIVENESS OF APPROACHES IN MEETING EXPRESSED NEEDS

The specific needs of persons with disabilities and their families in low income urban communities expressed in the three community studies, and in order of priority, are for:

1. Work and income
2. Education
3. Appropriate medical rehabilitation

4. Inclusion in urban development
5. Acceptance in the community

3.2.1 Meeting the need for work and income

One segregated centre-based vocational training evaluated was located in an urban area but had a mainly rural user group. Urban youths with disabilities described that the trades offered were old fashioned and not oriented to the skills needed for urban employment. They said that better training was available in mainstream vocational government training centres, and even in small businesses, which would offer skills more appropriate to local urban market opportunities, and would be of better quality. One young man commented that "education and training are important, but there are children who get jobs at the age of 12 and learn to do soldering straight away - and some of us go to school and then Industrial Training Institute and still don't do it as well!". This centre was also organised to support mainly male trainees by firstly offering trades favoured by men and secondly advertising for applicants from 'boys'. It also largely limited itself to those with polio-related moving difficulties, although people with speech and hearing difficulties and mild learning difficulties were beginning to be accommodated, though in informal trades which did not receive a government-recognised certificate. It is reported that job placement following this training is successful, although records were insufficient to follow this up.

The other two centre based vocational training services included more people with other moving difficulties and learning difficulties, although one of them screened trainees in favour of those with least difficulties.

In one centre there was a feeling amongst some parents of trainees that the vocational training was actually a form of therapy or an adult day centre. The ex-trainees interviewed had had mixed success in earning money in the mainstream. By the organisation's own estimate, only 3 of 49 current trainees came from 'lower class' households.

The other centre is more actively oriented towards paid work. Some trainees are placed in local businesses, although the major single employer is the organisation itself. Some of the placements followed up were not financially viable for the individual placed. For those with severe and multiple impairments who had fewer opportunities for mainstream employment, training outcomes were oriented towards establishing income generation using family resources. Some of these units were actually supported almost entirely by the work of other family members, but persons with disabilities were to some degree present during working hours. The income benefited the whole family, and such a need for household-based production was identified in the community study. However, from the partners evaluated, success appeared to depend on considerable existing financial resources of the family. These included considerable start up capital, and space in which to set up work, which virtually excluded the urban poor.

There was one example of a community-based approach to vocational training. This organisation included persons with disabilities and their family members, mainly mothers, in its own community based vocational training centres, and in centres run by other organisations. This was part of general community development. After training, people reported that they were able to take up better work in the local garment manufacturing industry. In fact, the community workers complained that once trained these slum dwellers earned more than they did. In general, any vocational training was only as good as the quality of the skills offered and the availability of local market opportunities in which to employ them.

The community study indicated that most opportunities for paid work for persons with disabilities arise in their own communities, although these are mainly those with moving difficulties. Such opportunities for paid work develop from family resources and local social contacts such as friends and neighbours. Therefore, removing persons with disabilities from the community environment, whether for school or vocational training, would appear to reduce such mainstream job finding opportunities. If placement follows vocational training, there is also a need to orient other workers to a person with disability. Discussion with persons with disabilities and their families also indicated that segregated training reinforces expectations for special services such as government reservations and pensions, which are almost completely unavailable.

3.2.2.1 Access to welfare: The centre based schools appeared adept at securing government scholarships, and disability certificates for children with disabilities. These were often applied for en masse and a greater proportion of these school children had benefits than the proportion of children in the community study. However, such facilitation of access to benefits was not apparent for children using occasional services such as OPDs. Given the tendency for those using daily services to be from more affluent households than those using less frequent services, this differential support is inequitable.

One of the partner organisations, managed by a person with disability, had the explicit aim of helping all groups of disabled adults to gain access to state and national government services for disabled people. However, reports by persons with disabilities who had contact with the organisation raised doubts about the success of this process. They reported that the organisation's director demanded payment for this service, did not always secure benefits for them, and even that he had applied for plots of land under the state government's disability quota, and housing loans on their behalf, and sold the plots to other people and kept their loans. Persons with disabilities are not necessarily more sensitive to the needs of other persons with disabilities.

3.2.2 Meeting the need for education

The community study described the importance of education in mainstream schools for those children with disabilities who do go to school, and the far greater numbers of children with disabilities in mainstream schools than in special schools. However, many children from low income communities do not go to school at all, and this is not limited to children with disabilities.

Home based, community based, and centre based approaches support some children who are in mainstream school. Given the different difficulty groups served by each, it is difficult to make comparisons of the relative success in supporting mainstream placement. For example the community based approach has placed mainly those with moving difficulties resulting from polio, so it is not reasonable to compare this with centre based services' more modest levels of placement of those with cerebral palsy. In general, mainstream placement was restricted to children with moving difficulties.

Although the centre-based services have some users who do go to mainstream schools, this support is fairly passive: children in such schools come to the rehabilitation service for additional support, rather than the service actively putting children into the mainstream. The experience of such children was that they had to miss school, or wait for holidays, in order to visit rehabilitation workers. This was the case whether needs were for medical rehabilitation, emotional support, or to address other problems at mainstream school. Centre based OPD staff were generally unable to make visits to school or home on behalf of children with disabilities using the OPD.

In home based and community based approaches, mainstreaming is supported by generalist municipal community workers, and an NGO's community social workers. Overall support for children who can enter mainstream schools is best delivered by such community based workers working closely with local schools' teachers. This enables sustained and flexible interaction in home and school visits, which is needed, particularly when placement is new to a child or new to a school. This is true for all types of education, from pre-school and informal education to primary, secondary and further education. The evaluation suggests that the best approach to mainstreaming is by community workers supporting children with disabilities and orienting local education structures to integrating persons with disabilities. The evaluation indicates an ideal where community workers and education workers should be part of the same integrated structure which addresses the needs of all children, whether excluded because of disability or because of poverty.

The success of the approach to mainstreaming children with seeing difficulties by providing integration training for children and training teachers to support children with disabilities in mainstream schools is uncertain. An absence of records meant that very few children who had been through this process were traced, and none came from urban low income communities. What is more, a proportion of the teachers trained went on to work in special schools.

3.2.2.1 Effectiveness of special schools: The evaluation aimed to evaluate the effectiveness of the special school approach in meeting the needs of children with disabilities from low income communities, and not to make a detailed educational assessment of the quality of special schools.

The community study found that the number of children with disabilities attending special schools (56) was about five times smaller that the number attending mainstream schools (253). This limited coverage was also apparent within the partner organisations, where the number of children with disabilities attending special school services was a small part of total coverage. This was in spite of the wider age group attending special schools (such as 5 years to 20 years) when compared with related OPD services (1 year to 8 or 10). What is more, many of those attending OPDs had no regular educational inputs other than a half hour session with a special educator twice a month at the OPD.

Two of the three special schools include mainly those with severe and multiple impairments However, each of the three include some children who could be in mainstream education with appropriate support. Some parents of children voiced concern about the impact of segregation on their children.

The three special schools included in the evaluation were already operating at maximum capacity and were unable to increase their intake. In relation to coverage, two of them were described by service providers as 'model schools' to be replicated by other organisations in other places in order to include more children with disabilities in education. However, the cost of special schools (see section 3.6) makes replication very difficult. There is insufficient money available in the public sector, and the partners were all long established and adept at raising their own funds. The likelihood of funds being available for replication is slim.

3.2.2.2 Learning for people with severe and multiple impairments: The community study indicated that there is a significant need for more basic learning for people with multiple and severe impairments which was unmet by government services. Centre based special schools and OPD offer inputs for learning daily living skills. In the centre based approaches evaluated this learning is supported by a professionally trained special educator and therapists. The most intensive support available for learning daily living skills is at special schools, but there are barriers to successful learning of skills. Firstly, special schools are not available to many persons with multiple and severe impairments from low income communities. Secondly, other family members are usually not present during school sessions which limits the role of the parent in continuing the teaching at home. Centre based OPDs have a greater coverage of low income groups and present an opportunity for persons with disabilities and family members to share skill-oriented programmes and practice them at home. Demerits are that the frequency of inputs in an OPD model is less, particularly for low income users. However, the major problem associated with learning skills in all centre based services relates to the need for such learning to take place in as normal and constant an environment as possible. A strange place and strange people make learning more difficult for persons with disabilities and their family members. The centre based services address skill learning in an environment inconsistent with the physical, social, and cultural environment in which such skills will be applied.

Firstly, the OPDs evaluated took place in large spacious buildings with decoration, furniture, and aids not found in the homes of the urban poor. Programmes for toiletting could not be practised with the therapist present as the toilets in the service centre were very different from toiletting opportunities in slums. The same is true for feeding: practical training is not possible if food is unavailable in centre based sessions, or if sessions are not held at appropriate meal times. Secondly, in each organisation evaluated, rehabilitation professionals come from higher socio-economic groups than the urban poor. They communicate differently, both in terms of language (e.g. English instead of local languages) and qualitative differences in idiom and dialect. Some therapists were unable to explain activities in appropriate terms. In some cases, advice given by professional therapy staff displayed a lack of understanding of life in low income communities, particularly in relation to a material environment that did not exist. Whereas the special school services evaluated have opportunities for therapy staff to make home visits, this was not the case for OPD.

Outreach approaches in low income communities place skill learning closer to the physical, material, and cultural conditions of persons with disabilities' homes. However, outreach centres can still have the same barriers to appropriate skill learning as service centres. For example, although outreach centres have a day care function which allows family carers time for other activities such as work, some joint contact is necessary if skill learning is to be practised at home. In the only outreach centre in a low income community evaluated, the building had no toilet. Children were taken to a nearby house, but young adults who did not have bowel control were excluded. Sessions were arranged either side of lunch time, so feeding was not practised. There appears to be a need for outreach sessions to at least be combined with home visits. Although this was part of the outreach programme, in practice home visits were not pursued and learning did not take place in the home. The community based approach did combine activities in this way.

Although the best learning environment is in the home, the evaluation found that workers must have the appropriate skills and support to maximise the use of this environment. The generalist rehabilitation workers were not addressing needs for daily living skills. They ignored these needs, or offered stereotyped verbal advice rather than holding goal oriented practical activities for learning. The classic example is the advice for toilet training that a persons with disability "be taken to the same place at the same time every day" but with no follow up or practical assistance. This appeared to be because the workers were generally de-motivated by their low honoraria, insecurity, and absence of technical support in the community. Also, their recent training inputs had been classroom based and given by centre based professional therapists, and covered theory (such as anatomy) but was not followed up by practice. The same problem was true for physical management.

3.2.3 Meeting the need for medical rehabilitation

Research tools used in the tracer study are included in the appendices. The tracer study assessed 5 dimensions of quality;

A. Management by use of goals
B. Interpersonal quality
C. Daily living skills
D. Appropriate education or work plan
E. Technical quality

The tracer method was applied to service use by low income persons with disabilities. This caused some difficulties as the number of low income users of some service approaches during the evaluation period was very low. Similarly, the numbers of assessments made for each difficulty group was low because of the small numbers of people available. However, the tracer method does not aim to be a quantitative method. The tracer study was applied to four service approaches in which medical rehabilitation sessions were delivered by the following types of staff:

1.	Home based	generalist rehabilitation workers
2.	Community based	physio aides and special education aides
3.	Centre-and-outreach	mixed physio aides and professional therapists
4.	Centre based	professional physiotherapists and special educators

A. Management by use of goals:

Assessment of the management of an individual's medical rehabilitation was made on the assumption that good practice involved the setting of functional goals with which to structure physical management and other inputs. All of the persons with disabilities assessed had goals recorded in their records. Good practice would be indicated by the following relationships. Goals should be recorded and used as a reference by service providers in each session. This was assessed by comparing the goals given verbally by the service provider immediately after a session with goals recorded in a child's records. Good practice was determined by convergence between these goals. Goals should be agreed in consultation between carers and service providers. This was assessed by asking carers to list their goals and comparing these with those listed verbally by service providers. Good practice was determined by convergence between these goals. In the table below, convergence is presented in the form x/y where x represents the number of assessments in which convergence took place, and y represents the total number of assessments made. Therefore, 8/12 indicates that there were 8 examples of convergence in 12 assessments. To generate comparative scores, these fractions have been calculated as decimals.

Table 16: Management by use of goals

service approach	staff type	Convergence between goals of service provider and user's record	Convergence between goals of service provider and service user
1. Centre	professional physiotherapists and special educator	12/15 =0.8	9/15 =0.6
2. Centre-and-outreach	mixed physio aides and professional therapists	8/12 =0.6	9/12 =0.8
3. Community based	physio aides	10/13 =0.8	10/13 =0.8
4. Home based	generalist rehabilitation workers	0/20 = 0.0	9/20 =0.5

The use of goals in centre based, outreach, and community appears quite common with convergence in between 0.6 and 0.8 of cases in both tests. It should be noted that these approaches involved i) professional physiotherapists and special educator ii) mixed physio aides and professional therapists and iii) physio aides alone, with all proving adept at management by goals. In the home based approach delivered by generalist rehabilitation workers, practical goals had not been discussed and there were no recorded goals.

B. Interpersonal quality

Quality of interpersonal processes was approached across a range of observational measures and questions to persons with disabilities and their family members. A score for interpersonal quality was calculated by dividing the number of measures passed by the number of measures applied. The score for each service approach were: centre 0.9; centre-and-outreach 0.8; community based 0.9; and home and referral 0.6. Quality was impressive in centre based, outreach and community based service approaches. The interpersonal quality was least good in the home based approach using generalist workers. This was because service visits were of short duration, often perfunctory, and workers failed to offer any skills for home use. Instead they

For all service approaches, performance against the impairment specific minimum technical standards were poor. The type of worker delivering the medical rehabilitation had no overall influence on technical quality. For example, none of the approaches, including the centre based professional service met the minimum technical standards for cerebral palsy. In each impairment group, there common reasons for the services failing to attain minimum standards:

1. **Cerebral palsy**: there were no records maintained of people's contractures, even when contractures are apparent and physical management applied to prevent development of contractures. This deficiency was important in the zero score for the centre based approach - ignoring failure to record contractures, the pass rate was 14 out of 15 and for the centre and outreach approach which had an amended pass rate for cerebral palsy of 5 passes in 9 assessments.
2. **Polio**: some aids, appliances, and surgery were provided with no impact on functional ability. This was particularly the case in the home based approach in which referral was the major service offered. Service for those with less serious moving difficulties passed the assessment; those for serious moving difficulties failed.
3. **Communication**: in failing assessments, service providers insisted on speech, and ignored total communication
4. **Epilepsy**: none of the assessments for people with epilepsy passed minimum standards. Responsibility for managing fits is passed to medical institutions. However, neither these referral institutions or the partners address needs for access to appropriate information about i) the background to the condition, ii) managing fits and iii) what to do when someone has a fit.
5. **Learning difficulty**: service provider does not address all needs for daily living skills. Appropriate inputs for daily living skills were particularly absent in the home based approach when workers largely ignored functional needs such as toiletting skills.

Summary of tracer study assessments:
The relative quality of the different models indicated by the tracer study:

Quality measure	←HIGH QUALITY	.... LOW QUALITY→
1. Technical quality	Centre based Centre-and-outreach	Home based
2. Management by goals	Community based	Home based
3. Interpersonal quality	Centre based	Home based
4. Daily living skills	Centre based	Home based

3.2.3.1 Other quality issues

Aids, appliances and surgery: the community studies found that many people that had been supplies with aids and appliances were not using them. Observation indicates that compliance with use of aids and appliances is greater in centre based services, although use of a calliper in school did not mean that it was used at home. Indeed, for children with disabilities from low income households, wheelchairs used in special school are often left at school as they are unsuitable for home use. Others reported that they did not use aids and appliances during the school holidays, even if there was contact with service workers during that time.

At least one community study raised concern about the functional impact of corrective surgery in that city and indicated a need for a dedicated evaluation of surgical referral. One of the home based services made referral for aids and surgery a priority activity without any follow up to assess the effectiveness of interventions. There is a need to recognise the functional limits of aids, appliances and surgery and to monitor the effectiveness before more persons with disabilities are referred. In this home based approach with medical referral, qualitative evidence suggests that the high level of referral for corrective surgery is driven more by the presence of a centre famous for the quantity of such surgery particularly for poor people, than by persons with disabilities' needs for corrective intervention or by the success of past intervention.

Physical management: in all organisations, persons with disabilities and their families do not frequently practice physical management exercises, particularly if passive movements are advised. Practice is time consuming and boring. Physical management based on positioning and daily activities appears to be better sustained.

Physical management delivered in centre based services is, like other aspects of the service, divorced from the reality of poor urban households. Some service deliverers are adept at making physical management active, interesting and relevant, with an emphasis on activity rather than exercise, but this is by no means the norm. With a high turnover of therapists (see section 3.3) the quality of the most experienced therapist does not always influence the practice of short term staff, some of whom suggested exercises which would be impossible in the small space and poor material environment of a slum house.

The evaluation suggests that the best location for home management is in the community or home environment. However, all home and community based home management was passive and thus rarely sustained by persons with disabilities and their families. There was little flexibility or creativity to make it more relevant to the every day life of poor urban families. All workers demonstrated a need for regular technical support and ongoing training inputs.

Emotional support and counselling: The centre-based services have polarised extremes of counselling. Children in the three special schools evaluated have regular group counselling sessions from social workers, who also respond to individual needs, offer group sessions for parents, and make home visits. This intensity of counselling provision is in contrast to that available to users of OPD services. During OPD sessions with therapists and special educators, there is little time for counselling despite the presence of social workers, whose major role is assessing socio-economic status for calculating subsidies and keeping user records. In at least one OPD and also the outreach approach in the same organisation, the role of social workers was undervalued and was largely unplanned. Therapy workers questioned what social workers were for, and yet offered little when service users described problems related to social factors. Indeed, it was observed that when poor people did raise problems associated with poverty, centre staff said "that is not our field" and focused on medical needs alone. Social workers should ideally have a clearly defined role and help other staff to be aware of wider needs. The OPD environment, and indeed all centre based facilities are far from ideal for counselling for families from low income communities who expressed feelings of unease when visiting the centres. Parents felt less able to ask questions and, of course, had to overcome barriers of distance to do so. Unlike special schools, additional opportunities for parent: staff contact are rare. Home visits are the exception rather than the rule. In centre based services, this difference between school and OPD is also experienced in 'peer counselling' and emotional support from parents' groups. Such groups are based around special schools which include few parents from low income communities.

Emotional support was a strength of the community based model. In this approach, each social worker covered just one community, and spent most of their time making home visits and supporting community activities. They had support from therapy aides and so were less likely to focus on medical rehabilitation needs only. The comprehensive nature of activities, taking in community health, socio-economic development, and credit groups mean that they were able to counsel and offer practical help for a wide spectrum of poverty issues not directly related to a child's impairment.

In the home based approaches, workers come from the same socio-economic stratum as people in low income communities so have a good understanding of needs. The quality of counselling and emotional support depended largely on the personality of the individual workers as training in counselling skills was negligible, as was on-going support. Some workers, particularly women, were diligent and sensitive while others were not, particularly as their own morale declined. For even the most sensitive and able workers, good work was impossible when their rehabilitation service was rejected by families when it was unable to address their prioritised needs.

From the evaluation of the disabled peoples' and parent originated organisations, it was clear that staff who are persons with disabilities or parents can offer considerable insight and appropriate emotional support. Parents have found support from each other to be of considerable value. However, this is by no means always the case. A need for understanding of disability must be complemented with understanding of poverty if persons with disabilities and their families from low income urban communities are to be supported. Services provided by persons with disabilities do not necessarily address the needs of persons with disabilities if a gap in socio-economic status separates the two.

3.3 STRUCTURAL ISSUES AND SUSTAINABILITY

The eight rehabilitation organisations have different staff structures, variously using professional rehabilitation staff; para-therapy workers; generalist rehabilitation workers; and combinations of these to deliver services. All but one of the partners had been in existence for between 10 and 40 years, therefore were sustainable in themselves.

The centre based professional approaches have all suffered from a shortage of available therapists and a high turn over of these staff. Staff leave because salaries offered by these rehabilitation NGOs are lower than in government sector and work hours are higher, leaving little time for private practice. In at least one of the centres, the quality of OPD service was adversely affected by a shortage of professional therapists on an on going basis. However, despite this shortage and the fact that it trained non-professional therapy workers for other organisations, this organisation eschewed the use of workers who were not professionally qualified in its own service provision. Given the shortage and salary costs of professional therapy workers, others train and employ non-formally trained staff. One of the centre based services for children with severe and multiple impairments was training mothers from low income households to become rehabilitation workers. One explicit reason for this was that such mothers of children with disabilities were less likely to leave the organisation. They did not receive formally recognised training so they were less likely to leave to take up better paid jobs elsewhere. However, they were asked to attend the organisation as volunteers for up to two years before training or payment. This was regarded as necessary to test their commitment, but was financially impossible for most mothers and is perhaps a contributing factor to the fact that only three were trained in a two year period.

If workers live in the same communities as low income persons with disabilities, they are more likely to be culturally, linguistically, and socio-economically attuned to their experiences and needs, and able to address them within a familiar environment. However, this appropriateness does not guarantee quality. It means little if training and support of workers is heavily oriented towards activities outside the community such as medical referral, if training inputs are of poor quality and do not empower workers to utilise their community knowledge, and if workers' morale is low.

In the two municipal home based approaches the 'workers' are volunteers paid a monthly honorarium. Worker morale was a key determinant of service effectiveness and sustainability. The major issues affecting morale were:

i) **Insecurity and lack of tenure**: People had joined the work with the expectation that their voluntary status would be regularised and they would become permanent employees. However, this has not occurred and what is more, regularisation has now been stopped and in both cities the future of voluntary workers' contracts, entire rehabilitation activities, and the wider development activities were in doubt.

ii) **Low payment**: Volunteers' honoraria have not kept pace with the rising cost of living. In both cities, the main reason for low quantity and quality of rehabilitation work was their inability to survive on the honorarium paid. Most volunteers had been forced to take other paid work which affected their work with persons with disabilities. In the two cities, the failure of municipal authorities to sanction allowances for transport and training also caused financial distress, and had a negative impact on community work.

iii) **Lack of recognition for work**: In both cities, rehabilitation workers were expected to do more work and work longer hours than their peers in general community health and development, despite getting paid the same honorarium.

iv) **Secondment for other duties:** Rehabilitation volunteers were frequently detailed for other activities which interrupt their work with and for persons with disabilities and their families. These are of varying legitimacy, ranging from health monitoring and anti-malaria drives to attending functions for visiting donors and election duty.

There is considerable evidence to suggest that unless these issues are addressed, the use of low paid volunteers by the Indian government to work with persons with disabilities and their families will not be effective or sustainable.

The NGO non-professional workers in the community approach also complained of similar problems related to low pay, but it appears that they are able to be motivated to continue quality work. In their case, low wages were attributed by the NGOs employing them to restrictions placed on wages by the international donors which support the activities.

3.4 PARTICIPATION

3.4.1 Staff participation

It appears to be the nature of rehabilitation NGOs that in the early development they depend heavily on the personality and vision of a single person. Such dynamism is important, but can have various negative effects. Firstly, when decision making falls to one individual, goals and vision may not be shared, or even known, by the other workers. Thus, while the chief functionary may see activities based on empowering persons with disabilities and their families, those at the interface between organisation and persons with disabilities may deliver services using the welfare model. Secondly, with executive power in the hands of one individual, service sustainability beyond their working life can be threatened. A more participatory and sustainable approach was present in another centre-based service in which executive responsibility was shared collectively by senior staff.

3.4.2 Participation of persons with disabilities and their families

In any organisation, any persons with disabilities' groups and parents' groups, will, in composition and interest, reflect the socio-economic constituency of service users. In the centre-based parent groups observed, discussion centred on issues such as tax relief for parents of children with disabilities, and special allowances for government officers to avoid transfer away from the city of their child's rehabilitation service. Such concerns are exclusive to higher income groups. It is important to realise that rights organisations do not represent all persons with disabilities and their families if participation of, and the needs of, the poor are not included. Centre based special schools do not include the urban poor and parents' groups do not address the needs of the urban poor. Opportunities for the participation of people using OPD services are virtually nil. They don't come frequently enough to build networks and service use is equated with hospital visits; the concept and opportunities for involvement beyond passive receipt of therapy are absent.

Participation of persons with disabilities and their parents in the outreach centre covering a low income user group was gradually developing, and was being encouraged. However, it was clear from interaction with parents and local staff that they were in awe of the visiting professional support staff and thus had not increased the horizons of their participation very far. Regardless of the statements made by the professional staff about processes of community involvement and hand-over, the parents and staff were largely unaware of these and perceived the centre based service as the source of key decisions and resources.

In home based services, participation of persons with disabilities and their families is limited if active and empowering participation is not an objective of the municipal structure of which the activities are part. The experience of both partners was that although participation of slum dwellers was explicitly part of the development process and was supported by participatory training for staff, it had no obvious effect in facilitating the participation of persons with disabilities or their families. In fact, in one, the priority needs expressed by persons with disabilities and their families which were for income and education, were ignored by middle level municipal functionaries, who steered activities toward medical referral.

The most advanced participation of persons with disabilities and their parents from low income communities was experienced in the community based model. A long term presence in the community, an evolution towards community control, and a comprehensive approach to development for and with persons with disabilities which included medical rehabilitation, education, income generation, credit groups, community health, cultural activities and sports for them and their family members, had facilitated considerable participation which had grown well beyond the limits if service use. An indication of the level of this participation was the fact that persons with disabilities were empowered to express their complaints about the service provider during evaluation meetings.

3.5 ADVOCACY, AND SELF ADVOCACY

Throughout the evaluations, 'rights' generally focused on disability issues such as reservation, and not on the rights of persons with disabilities to enjoy equal opportunities as other citizens. Persons with disabilities, parents and staff had little to say about wider rights issues, and rights were not used as a frame for activities.

To a degree, centre based approaches advocated the rights of persons with disabilities to government benefits, but this was virtually limited to users of daily services, of whom very few were poor. OPD sessions have little time for discussion of rights. Additional workshops have been organised, but these demand an additional journey to the centre. One centre now has a person with disability trained in advocacy issues to lead workshops with service users and staff. However, the degree to which this will address the issues of disability and poverty, and the rights of persons with disabilities in slums, is not assured. Sensitivity to disability does not guarantee sensitivity to the lives and needs of poor people.

In home based and community approaches, awareness of rights was mixed. Where empowerment and participation of staff and service users was developing, the concept of rights as a frame for development for persons with disabilities was growing. Where staff at the interface with the community had little power and persons with disabilities were viewed as passive recipients, rights had little practicality.

3.6 THE COST OF APPROACHES TO SERVICE PROVISION

The calculation of comparative service costs is difficult given the nature and variety of the rehabilitation services evaluated. Calculating the costs with a view to comparison between approaches is even harder. The different approaches serve a variety of user groups defined by impairment and age. Urban persons with disabilities and their families have an endlessly varying situation of experiences and needs, depending on impairment, available support, early intervention, previous rehabilitation activities and crucially, socio-economic status. There can be no measure of effectiveness with which to set against cost, and even attributing a crude cost to each service user is difficult given the varying frequency and duration of service sessions. However, calculation of the annual cost of each service per capita has been attempted. This is based on the annual budgetary data available from each partner. It does not include the capital cost of setting up centre based services. It uses estimates of the number of users of each service; this too was problematic as these might include those who use services daily, and those who have contact once a year.

Table 18: Crude annual costs of service use per person with disability served

Service approach and user group served	***estimated number of service users***	***Total cost of service per year (Rs.)***	***crude cost per user per year (Rs.)***
Centre with outreach cerebral palsy, and multiple difficulties			
1. Special School[12]	64	6,57,631	**10,275**
2. Vocational Training Centre	49	5,89,298	**12,026**
3. Out Patients Department	233	4,50,179	**1,932**
4. Outreach centres[13]:			
i. parent group	*9*	*1,76,397*	*19,599*
ii. slum school	*14*	*2,61,314*	*18,665*
iii. slum school	*12*	*1,72,615*	*14,385*
iv. special unit	*12*	*1,22,715*	*10,226*
v. peri-urban	*12*	*98,715*	*8,226*
vi. welfare campus	*15*	*1,21,195*	*8,079*
5. Outreach centre in low income community	16	87,354	**5,460**
mean outreach cost	*90*	*10,40,305*	**11,559**
Centre based cerebral palsy, plus multiple difficulties			
1. Out Patients Department	418	4,71,008	**1,127**
2. vocational training centre	40	4,64,240	**11,606**
3. Special school	200	2,456,800	**12,284**
Centre based mainly moving difficulties			
1. vocational training centre	60	6,55,152	**10,919**
2. Special School	200	10,56,986	**5,285**
Community based mainly moving difficulties expanding to all difficulty groups	531	14,18,667	**2,669**
Home based with medical referral all difficulty groups	250	4,20,816	**1,683**

It must be noted that the centre based costs presented above do not include the costs borne by the service users. For example, the mean transport expenses for OPD users in the first organisation in the table were Rs.29.9 per visit and the mean number of visits per month was 2.6. Assuming constant service use over a year, a crude mean cost of transport per year for OPD users can be calculated as Rs.727. Thus the cost of service provision of Rs.1,932 per service user per year increases to Rs.2,659 if transport costs are included. The crude transport costs per year for the second OPD can also be calculated: the mean number of contacts per month is 1.7; the mean cost of transport is Rs.26.8; and the crude mean cost of transport per year is Rs.579. This makes a combined cost of service provision and transport of Rs.1,706 per year. These figures would increase further if other costs such as food and work time lost were included. When comparing the cost of OPD with community based services it should also be noted that the mean frequency of service contact in the OPD described is 1.7 times per month. The mean for the community based service was 10.4.

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[12] costs do not include any building costs.

[13] the costs of seven centres were estimated. Only one was in a low income community and not part of a larger institution.

SECTION 4 TOWARDS A MODEL OF URBAN COMMUNITY BASED REHABILITATION

The project has explored the needs and experiences of persons with disabilities and their families in low income communities and evaluated current models of delivery of disability services to the urban poor. It was anticipated that one of the approaches or a combination of the elements from different approaches, would emerge as a model for urban community based rehabilitation. There were unfortunate administrative delays in the implementation of the integrated model (see organisation 5 in table 1, page *) proposed as early as 1990, and this was not the case. However, the study found compelling evidence that suggests that certain characteristics would be appropriate in such a model, and a theoretical model emerges from this study evidence.

A model is a conceptual guideline or ideal which can be practically adapted to meet a specified objectives and outcomes. This ideal should be understood by all those involved.

The objective of this model is inclusion of persons with disabilities in all mainstream activities through equalisation of opportunities.

- It is a strategy integrated into all development activities in urban areas
- It will integrate with existing structures, rather than duplicating them
- It is not a centre based or outreach model
- It starts from the planning commission and works throughout all ministries through to local bodies and their activities.
- It is not a scheme only of the Ministry of Welfare.
- Persons with disabilities and families participation is a prerequisite for this model.

Government should cover the aspects which it can do, such as infrastructure development, education, and transport. NGOs should do the things that they are good at, such as mobilising communities.

All action should be channelled though urban bodies and community development structures, and should not be medicalised.

At the local level the appropriate body for implementation is the municipal authority and not the metropolitan development authority. The GOI proposed urban community development societies, which will play a key role in converging a variety of sectoral inputs at the community level, will also play a key role in this model.

The front line workers are suitably paid urban community development workers of the local body who should be equipped to include persons with disabilities in their activities. They will be supported by full time community development specialists trained in social aspects of disability such as inclusion, the social model, the barriers approach, and technical aspects of impairment and disability.

There is a precedent of the Ministry of Rural Development's CAPART (Council for the Advancement of People's Participation in Rural Technology) initiatives in rural areas of promoting a scheme to encourage persons with disabilities to organise themselves. In a similar manner, community facilitators (animators) will be needed to organise groups of urban persons with disabilities and families to formulate their needs and express them to service providers. The services should not be pre-determined, but should develop with service providers in a flexible way. The community facilitators will work for two to three years with a given group of persons with disabilities and will move on to other localities. It is expected that during this time, groups of persons with disabilities would have developed sufficient leadership to be self sufficient and support other groups. They should be full time as they will work with many communities and should be adequately paid.

Government (Ministry of Urban Development and Ministry of Welfare) should fund mainstream NGOs to employ the facilitators to do this work. Training of facilitators should be by NGOs which do general development training, with additional inputs on disability, and not by disability organisations.

Medical rehabilitation referral will be from community workers to existing government and NGO centres but should be limited to interventions that can only be done in centres. The study found that poor people cannot come to centres therefore the centres should share skills with families and community workers who can apply them in the community.

Disability NGOs' role is limited to skill sharing and referral where these cannot take place in the urban community. The role of disability NGOs experienced in community work is to inform mainstream development NGOs on how to include persons with disabilities in all of their work..

All service providers' capacity to respond to the needs of persons with disabilities and families will be developed through awareness workshops and appropriate technical orientation. The inclusion of persons with disabilities should be seen in a similar way to gender work and financed accordingly.

The outcome of the model should be the inclusion of persons with disabilities in urban development, inclusive education, work and training, and all mainstream activities.

SECTION 5 CONCLUSIONS AND POLICY RECOMMENDATIONS

Introduction:

This study approached the needs and provision of services from the perspective of poor urban persons with disabilities. It is was known that services for persons with disabilities in both NGO and Government sectors exist in urban areas. This study aimed to examine if they reach poor urban persons with disabilities, and if they meet real needs. The study did not specifically examine all available service structures individually.

The policy recommendations described below are output of the study, and from discussions at the three city workshops and national workshop. They have been developed to the extent possible following this process. Identifying opportunities for further developing links between the needs of persons with disabilities in the community and the existing structures at state, central and NGO sectors, requires further dissemination of the findings of this study within those structures an examination of opportunities with those structures.

Some structures are already present such as the Project Integrated Education for the Disabled (PIED), and VRC, but in practice the coverage is limited. For example, in the case of PIED, by 1995 it had been implemented in 10 demonstration sites in 8 states. However, these did not include the three cities included in the UCBR Project. In the case of VRCs, although VRCs have been set up in Calcutta and Bangalore (*check), none of the adults with disabilities sampled in the three cities had used VRC services. It appears that some developments have not had a significant impact on the urban poor as sampled in Visakhapatnam, Calcutta and Bangalore.

What the study has shown is that some integration of persons with disabilities is taking place. Some children with disabilities are attending mainstream schools. Some persons with disabilities are attending mainstream vocational training. Some persons with disabilities are working and earning in the mainstream of their community. Policy and practice should encourage this to grow.

1. Disability and poverty must be addressed together.

This study found that, whatever the situation of poor families, there were additional costs related to disability, and reduced opportunities for paid work, for persons with disabilities and their families. Poor urban persons with disabilities and their families should receive priority in mainstream urban development, not just through legislation but in practice.

1.1 The needs of persons with disabilities should be included in all mainstream development, including urban poverty eradication programmes.

1.2 The barriers that prevent this are economic, structural, environmental and attitudinal. These should be identified, analysed, and removed.

The principle of inclusion means that persons with disabilities and non-disabled people have equal opportunities to share in mainstream activities. It does not mean an additional, separate, provision under the same development structure. For example, in inclusive community development, persons with disabilities take part in mainstream skills training with non-disabled people: they are not offered a segregated version under the same budget.

2. Representation of poor persons with disabilities must be a foundation of their inclusion in mainstream development.

This study found that the priority needs expressed by urban poor persons with disabilities and their families are for income and education, priorities in common with poor non-disabled people. This study found one example of an organisation started by persons with disabilities which had enabled poor persons with disabilities and their families to give voice to their needs. Importantly, this organisation addressed the needs through a community development approach.

2.1 Policy and practice should enable persons with disabilities and their families from low income areas to organise themselves to express their own needs in the development process.

This study found that women with disabilities were significantly less likely to attend school or do paid work than men, and were perceived to be exposed to greater risks relating to community prejudice, lack of respect, and sexual violence. In addition to the usual burden of a woman's role in family life, women and girls took on considerable additional work in caring for persons with disabilities, often in isolation, and without additional support, or appreciation for this effort.

2.2 Policy must ensure the equal representation of poor urban women with disabilities and their female care givers to express their specific needs through a community based approach.

This study found that a barrier to persons with disabilities' inclusion in structures is the excluding attitude of staff in government departments, community development, public transport, hospitals, schools, NGOs, urban development, and donors. Attitudinal barriers reinforce economic, structural, and environmental barriers, and promote an atmosphere in which these other barriers are unlikely to be addressed.

2.3 Awareness and action training on disability and poverty, centred around the social model of disability and barriers approach, and lead by persons with disabilities, should be compulsory for all central and state government staff, municipalities, NGOs, donors, politicians, and elected representatives of the people.

Specific examples of opportunities for integrating persons with disabilities into a network of community development services, from the relevant Ministries' actions to community level structures, arose from the study findings from the city workshops, and from the National Workshop. These are included in detail in section 7 below. The most important examples are:

2.4 Planning Commission at the centre and state planning bodies: advisory committees should include persons with disabilities, and those with direct experience of working with persons with disabilities in poor communities using a community development approach. They should ensure the implementation of these recommendations in all planning processes.

2.5 All urban local bodies such as municipalities, corporations, and community development societies should ensure adequate resource allocation in their plans for the implementation of inclusion of persons with disabilities in all their programmes. This should include support for the informal sector, such as self employment schemes and allocation of space for small and medium sized enterprises.

2.15 All concerned state departments and undertakings should also develop and implement policies for the inclusion of persons with disabilities in their programmes.

2.6 Ministry of Welfare: in addition to expediting the appointment of the Commissioner and the implementation of the Disability Act, the Ministry of Welfare should co-ordinate and promote the inclusion of persons with disabilities into other ministries' policy and practice. It should also monitor the effectiveness of its own activities such as surgery, and supply of aids and appliances. The Ministry of Welfare with the Ministry of Health should review the current system of eligibility criteria as described above.

The study found that persons with disabilities were not being included in government, NGO ad donor funded activities. Recognising persons with disabilities' rights as citizens under India's constitution, their inclusion should be compulsory in government, NGO, and donor urban development activities. Inclusion can be enforced through budget allocation, much as all development budgets and activities must include the needs of women. Government and donors should adopt this as a pre-requisite to resource allocation.

2.17 Financial resources for urban development in government and NGO sectors should be allocated only when the inclusion of persons with disabilities is explicitly addressed in their planning and implementation.

3. Support the family and community

The study found the greatest support for persons with disabilities came from their own families, and their immediate communities, and not from government or NGOs. The greatest needs expressed by persons with disabilities and their families were economic. Those persons with disabilities who were working were doing so in family based and self employed petty businesses near their homes. Others, particularly those with severe and multiple impairments and their care givers, also needed emotional and social support. Mothers expressed the opinion that their support for their disabled family members would be easier if their family poverty was addressed.

3.1 Support, including money, should be given to family and community based income generation groups complemented by group managed day care, and emotional and social support.

Persons with disabilities and their families also wanted:

i. mainstream work.
ii. grants or loans for starting income generation.
iii. skills training.

Provision of loans for persons with disabilities already exist in India, but in the three community studies only one of 587 persons with disabilities interviewed had secured a loan.

3.2 The Disability Act, in relation to work in the organised sector, should be enforced.

3.3 Policy and practice should treat persons with disabilities as a priority group in micro- finance schemes.

3.4 Loans should be available to care givers when persons with disabilities cannot work themselves on account of their disability.

3.5 Both mainstream and poverty-focused skills training should be accessed by and adapted for persons with disabilities, and include basic numeracy and literacy skills.

This study found that government pensions for persons with disabilities are limited in number, inaccessible, and inequitably distributed.

3.6 Pensions should be allocated to persons with disabilities where the state is unable to provide, whether directly or indirectly, access to work, and priority should be given to those who require full time care.

The study found that more children with disabilities were served by local mainstream schools than by special schools.

3.7 Mainstream schools should be supported to include the needs of all children, including children with disabilities, within their catchment area by changing national and state teacher training curricula, the physical environment of schools, learning materials, and providing disability awareness training for all staff, non-disabled children and their families. Local resource centres to provide support for those with more complex educational needs should be promoted.

4. Centre based services do not meet the needs of urban poor persons with disabilities

This study found that centre based services which focused primarily on medical rehabilitation and segregated education do not include or meet the expressed needs of poor urban persons with disabilities. This study found that centre based services lead to unequal distribution of resources.

Centre based services focus on medical needs which are not the priorities of poor people. Medical rehabilitation has a limited role in meeting the needs of the urban poor. It is inappropriate for centre based medical services to manage community based services.

4.1 Medical services should demonstrate that they have practical contributions to make in relation to the needs of poor families and the strengthening of community workers. They should also demonstrate their coverage and effectiveness.

4.2 There should be education within community services about the limitations of medical rehabilitation so that excessively high expectations are not raised.

Poor people are unable to access centre-based services because of barriers related to the cost and time of travel. These become increasingly important when non-mobile children get older and heavier.

When persons with disabilities express needs for medical rehabilitation, the centre based medical and rehabilitation professionals tend to deliver services in a way that is socially, culturally, linguistically, environmentally and socio-economically divorced from the reality of the poor urban home. This study found that adaptation of centre based services to the needs of the poor, such as waiving user fees, and allowing infrequent attendance, does not ensure that poor people are included.

4.3 Granted that all services are inadequate, financial and skill resources should be directed towards community based structures that demonstrate that they effectively reach poor people. No additional resources should be put into centre based services unless they meet the criteria of equity (priority coverage of those most in need) and quality, and support community based approaches appropriate for poor urban communities. Resources for other centre based services should not be increased.

4.4 The existing resources and technical skills of centres should be used as a tool to support community approaches within a strategy of community development. Recognising the creativity and existing resources amongst poor families and communities, training needs (course content, methodology and materials) should be jointly and flexibly developed by persons with disabilities and their families, community workers and their organisations, together with professionals. This implies the reorientation of professionals to recognise the relationship between poverty and disability.

This gradual shift of resources from centres to community should determine the policy and practice of government, NGOs, and donors. For example, in the tenth five year plan, resources for community based approaches should exceed those for centre based services.

5. NGO and government roles

There is often an assumption that NGOs are more successful than government at reaching poor people at community level. This study did not find evidence to support this assumption at least for services for persons with disabilities in urban areas. In the three community studies, less than 5%

of persons with disabilities sampled had used NGO medical rehabilitation services. The number of persons with disabilities accessing government services in relation to their difficulties far exceded the number accessing NGO medical rehabilitation services. The study found that the most important determinant in reaching the urban poor was a community-based approach as part of general community development, rather than a centre-based service. This was true for both government and NGO services. As well as better coverage of poor people, community based services are delivered in a way more appropriate to the lives of the poor urban family. The NGO community based service evaluated was of better overall quality than the government community based services evaluated.

5.1 Allocation of resources for persons with disabilities should continue through the community development structures of both government and NGO sectors.

6. Monitoring and evaluation

This study found that coverage of urban poor persons with disabilities by service organisations is extremely limited, despite the fact that service providers thought it to be good. This indicates a need for improved monitoring and evaluation which measures both coverage and quality. For example, it is not acceptable to increase the coverage of poor people by running services which, in practice, differentiate the poor from the privileged. This study found that 88% of persons with disabilities had used medical rehabilitation services, mostly government hospitals, but the services received were of poor quality and expressed medical needs were not met.

6.1 Government, Municipal, and NGO service providers should monitor their coverage of the urban poor. They can do this by maintaining simple socio-economic information about their service users and compare this with socio-economic information from their city, for example from census and urban data bases.

6.2 Specialist medical, rehabilitation, special education, and community based services should be subject to appropriate evaluation of effectiveness and cost.

Monitoring effectiveness is also necessary to ensure that development meets the needs of poor persons with disabilities and their families.

6.3 Government and donors should make effectiveness in meeting the real needs of urban poor persons with disabilities a prerequisite of resource allocation.

This study found that government benefits have extremely limited coverage and are not equitably distributed. Significant barriers to access exist in government structures.

6.4 Government should monitor the coverage of welfare provisions such as disability certificates and loans, and address institutional and attitudinal barriers to their distribution.

7. Specific examples of opportunities for integrating persons with disabilities into community development services

Specific opportunities for integrating persons with disabilities into a network of community development services, from the relevant Ministries' actions to community level structures, arose from the study findings, and from the city workshops and National Workshop. Important examples are listed below.

The study found that access to water supply and in particular to sanitation caused difficulties for many people in poor urban communities but access was particularly difficult for persons with disabilities.

7.1 Ministry of Urban Affairs:. for ensure that all infrastructure, particularly water supply and sanitation, is accessible to all persons with different types of disabilities. All urban community development should include persons with disabilities in all activities, especially poverty eradication, for example Swarna Jayanti Sarkari Rojgar Yojana (SJSRY)'s thrift and credit programmes, Slum Improvement Projects, and the National Slum Development Programme, and the local bodies referred to in section 2.5 above. Women with disabilities should be prioritised in all urban development.

7.2 Ministry of Labour: ensure equal opportunities in employment and training for persons with disabilities by enforcing current legislation on disability, and enhance provisions for training and employment, such as integrating persons with disabilities into mainstream Industrial Training Institutes and Polytechnics, and extending legislation to include training and employment for those with learning difficulties.

7.3 Ministry of Education: develop and implement a policy of inclusive education whilst recognising the efforts that teachers have already made in integrating children with disabilities in many schools, and allocate resources to promote inclusive education. This includes changing national and state teacher training curricula, the physical environment of schools, learning materials, and providing disability awareness training for all staff, non-disabled children and their families. The Ministry should allocate resources such that persons with disabilities have equal opportunity to benefit from the Universalisation of Primary Education, mainstreaming them into the education system through condensed and bridge courses and open schools. Clusters of mainstream schools should be supported by resource centres to facilitate the inclusion of all children, including children with disabilities, within their catchment area.

7.4 Ministry of Women and Children's Welfare: ICDS and all other programmes under the Ministry, should include all women and children with disabilities in all policy and practice.

7.5 Ministry of Health and Family Welfare: channel resources to support persons with disabilities away from centre based medical services and into community based services. Community health workers should be taught about the realistic expectations of the role of medical services in relation to disabilities. The Ministry of Health and Family Welfare and State Departments should monitor the effectiveness of surgery, aids, appliances and other medical intervention for persons with disabilities. The Ministry of Health and Family Welfare, together with the Ministry of Welfare should review the current system of eligibility criteria for government benefits, and delegate responsibility for the issue of disability certificates to local health facilities.

7.6 Ministry of Finance: ensure that a quota is reserved for persons with disabilities in all schemes for financial assistance for self employment, and specific action to improve access to this quota is taken.

The Calcutta city workshop and National Workshop discussed the importance of the lack of information about available disability services and benefits at the community level as a barrier to access.

7.7 Ministry of Information and Broadcasting: promote programmes of successful inclusion of poor persons with disabilities in community based development programmes and positive images of poor persons with disabilities.

7.8 The various Ministries and Departments concerned with transport: actively address the issue of accessibility of all transport to persons with disabilities especially buses and trains.

APPENDIX 1: COMMUNITY STUDY INTERVIEW SCHEDULE (ENGLISH VERSION)

INTRODUCTION

READ: My name is ____________. I am a member of a team collecting information about the use of services for persons with disabilities. I would like to ask you some questions about your experiences, to help plan services in the future. This will take about twenty minutes. Anything that you say will be confidential.

FIELDWORKER CODE |__|__|

ELIGIBILITY CRITERIA

NOTE: persons with disabilities are eligible if they are not a user of any of the eight organisations NOW.

1a) Have you ever benefited from or used any organisation related to your disability? |*yes*| |*no* | *(if yes follow filter b below; if no - go to next question)*

if yes - *b)* What organisations have you used or benefited from? (*list*)

1
2
3
4

if any of 8 study organisations are mentioned go to c; otherwise go to Section A

c) Do you consider yourself a user of (*name relevant organisations*) now?: |*yes*| |*no* |

IF 'YES' - TERMINATE THE INTERVIEW AND EXCLUDE THE DATA *circle* **|excluded|**

if no → d) Why don't you use (*name organisation(s)*) now?

Section A -IDENTIFICATION SECTION

NB/ Ensure that you are recording details of the correct respondent

I1) Identification number |_|_|_|

I2) Means of identification/location: ____________________

A1) Person with disability's name: ______________________________

A2) Gender: *(do not ask)* |*m*| |*f*|

A3) age |_|_|

Aim to get real age. If impossible, classify in age categories

| |*16-20*
| |*21-25*
| |*26-30*
| |*31-35*
| |*36-40*
| |*41-45*
| |*46 +*

A4) Is the person accompanied (in the interview)? |*yes*| |*no* |

A5) Who is the respondent: |*person with disability*| |*other*| *(if 'other' follow filter b)*

if 'other' - b) Are you the usual carer? |*yes*| |*no* |

A6) Religion |Hindu| |Muslim| |Christian| |Other|
A7) Caste ____________________
A8) Household's first language ____________________

I now want to ask a few questions about where you live and your home:

A9 What is your address?: a) house details____
b) area ____

A10)Who is the main bread winner in your household (*name*): ____________________________
A11a) Gender of main bread winner: (*do not ask)* |*m*| |*f*|

b) Occupation of main bread winner (details):____
____

A12) Does this house belong to your household, or is it rented?: | |*Owned* | |*rented*| |*free occupation*

A13) ***OBSERVE - DO NOT ASK*** :

a) What are the walls of the house made of?
|wood| |plastic| |mud| |brick| |concrete| |other|

b) What is the roof of the house made of?

|plastic| |thatch| |metal| |tile| |asb. sheets| |concrete| |dk| |NR|

Section B- **USE OF SERVICES**

B1) What is your/(*name*)'s difficulty?

note in full and probe - full description, onset, cause,

B2a) Do you know the medical diagnosis of this difficulty?: |*yes*| |*no* | (*if yes follow filter b)*

→- *if yes b)* What is the diagnosis?

READ: I now want to ask you (*name individual*) some details about any services and organisations that you / (*person with disability's name)* have used in relation to your difficulty in (*give appropriate functional description*).

Read the question for each of the four categories in turn and follow questions a, b. Write notes with as much detail as possible.

Do not probe with examples - just use "anything else?" until exhausted. The only explanation given should be of terms such as 'welfare'.

		B3a)	B4b) What?: (write)
B3a)	Have you used any MEDICAL rehabilitation services/organisations to help with this difficulty?	|yes| |no |	
		B4a)	B5b) What?: (*write*)
B4a)	Have you used any EDUCATION related services / organisations to help with this difficulty?	|yes| |no |	
		B5a)	B6b) What?: (*write*)
B5a)	Have you used any EMPLOYMENT related services/ organisations to help with this difficulty?	|yes| |no |	
		B6a)	B7b) What?: (*write*)
B6a)	Have you used any WELFARE related services/ organisations to help with this difficulty?	|yes| |no |	

Section C - EDUCATION

NB/ *SECTIONS E AND F FOCUS ON THE SAMPLED INDIVIDUAL*

C1a) Have you ever attended school?: |*yes*| |*no* | (*if yes follow filter b; if no go to QC2)*

→*if yes* b) Do you attend school now? |*yes*| |*no* | |*NA*|

→ c) What is the highest grade class that you reached? (*circle one only*):

| 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | |10| |higher| |NA|

→ d) What type of school do/did you attend? (*tick for primary and/or secondary as appropriate*):

	PRIMARY SCHOOL	**SECONDARY SCHOOL**
tick one only for *for primary and* *one only for secondary* *as appropriate*			*special school* |	*mainstream school* | |*other (what?)* ____________ |*NA*|			*special school* |	*mainstream school* | |*other (what?)* ____________ |*NA*|

C2) Have you ever had any help with literacy? |*yes*| |*no* | |*NA*|

Section D1 - EMPLOYMENT

D1a) Do you work to earn money?: |*yes*| |*no* | (*if yes follow filter b; if no go to QD2)*

→ *if yes* b) What work do you do?: ________________________________

→ c) Is this **work** only for disabled people?: |*yes*| |*no* | |*NA*|

→ d) Is this **workplace** only for disabled people?: |*yes*| |*no* | |*NA*|

→ e) How did you get this work?: ________________________________

Section D2 - TRAINING

D2a) Do/have you ever received training to do work?: |*yes*| |*no* | (*if yes follow filter b; if no go to Q.D3)*

→*if yes*b) Are you training to do work now? |*yes*| |*no* | |*NA*|

→ c) What work are/were you training to do? ________________________________

→ *d)* Where do/did you do this training?:________________________________

→ e) Is/was this ***training*** only for disabled people?: |*yes*| |*no* | |*NA*|

→ f) Is/was the training ***at a place*** only for disabled people?: |*yes*| |*no* | |*NA*|

→ g) How did you get this training? ________________________________

FOR ALL D3) What work would you ***like*** to do?: ________________________________

APPENDIX 2: COMMUNITY STUDY FOCUS GROUP DISCUSSION PROTOCOL

PERSONS WITH DISABILITIES IN THE COMMUNITY

- Introduce participants
- Start the discussion guided by these headings
- Develop discussion using the non-leading probes developed in training and method notes from previous discussions

A. EXPERIENCE OF BEING A DISABLED PERSON IN THE COMMUNITY

A1. Ask each participant to briefly describe their history/their child's life

A2. What does it mean to be a person with disability in your community today?

A3. What are the needs of disabled people in your community? (List them on paper)

B. LIFE EXPECTATIONS:

B1. What are the expectations of disabled people in the community?

C. THE COMMUNITY AND COMMUNITY ATTITUDES:

C1. What effect do the community have on the lives and experiences of disabled people?

C2. What support for disabled people is there in the community

C3. What would change to make life better?

D. SERVICE USE AND NON-USE

D1. Which organisations and services have they used/visited/had contact with in relation to their disability (i.e. medical, rehabilitation, aids and appliances, welfare?)

D2. Have they heard of the partner organisations in this city?

D3. Have they used them (describe)

Appendix 3: Types of training experienced by persons with disabilities in 3 community studies

Place of training	Bangalore	Calcutta	Visakha patnam	Total
1. ITI (mainstream)			1	3
2. Training Institute (mainstream government)	1			1
3. Training Institute (segregated, Ministry of Welfare)	1			1
4. 'Vocational training for Physically Handicapped'		1		1
5. Indian Council of Rehabilitation (NGO)		1		1
6. Vocational Training Centre for the Blind (NGO)	1	2		3
7. Sranuk Vidya Peeth (NGO?)			2	2
8. Nehru Yuva Kendra (Govt, run through NGOs)			1	1
9. Segregated vocational training (NGO)			1	1
10. Special school vocational training class			1	1
11. Private business	3	8	3	14
12. Private training centre	1	3		4
13. Vocational training at school		1	1	2
14. Taught informally by local person		1		1
15. Local factory training		6		6
16. Family trade		2	5	7
TOTAL	**7**	**25**	**15**	**47**

APPENDIX 4: EVALUATION QUESTIONNAIRE (ENGLISH VERSION)

USER INTERVIEW SCHEDULE

INTRODUCTION AND IDENTIFICATION SECTION

READ: My name is ____________. I am a member of a team carrying out an independent evaluation of the services provided by (*name organisation*). Our work aims to help plan future services for persons with disabilities, and we are interested in the experience of those using the service now. I would like to ask you some questions about your use of the service today. Anything that you say will be confidential. The things that you say will **not** be disclosed to anyone in (*name organisation*) in connection with your name. FIELDWORKER CODE |__|__|

NB/ Ensure that you are recording details of the correct respondent
I1) Identification number |__|__|__| (for office use only)

I2) Location of Interview: | | *in home*
| | *centre in community*
tick one only | | *main organisation centre*
| | *other (what?):* ____________________

Section A - USER DETAILS

A1)User's name: ______________________________

A2) Gender: *(do not ask)* |m| |f|

A3) User's age |__|__|

Aim to get real age. If impossible, classify in age categories

| |*16-20*
| |*21-25*
| |*26-30*
| |*31-35*
| |*36-40*
| |*41-45*
| |*46 +*

A4) Is the user accompanied? |yes| |no |

A5) Who is the respondent: |user| |other| *(if 'other' follow filter b)*

→ *if 'other'* - b) Are you the usual carer? |yes| |no |

A6) User's religion |Hindu| |Muslim| |Christian| |Other|
A7) User's caste ____________________ |bc| |st| |sc| |fc| |N/A|
A8) Household's first language ____________________ (*mother tongue*)

READ: I now want to ask a few questions about where you live and your home:
A9) What is your address?: a) house details____
____b) area ________________________________

A10) Who is the main bread winner in your household (*name*): ________________________________
➔ what is the occupation of bread winner? : ________________________________
____

A11) Gender of main bread winner: (*do not ask)* |m| |f|

A12) Is it your own house or is it rented?: | |Owned | |rented | |free occupation

A13a) What are the walls of your house made of?
|wood| |plastic| |mud| |brick| |concrete| |dk| |NR|

b) What is the roof of your house made of?
|plastic| |thatch| |metal| |tile| |asb. sheets| |concrete| |dk| |NR|

Section B - USE OF THE SERVICE

READ: I now want to ask about your use of the service provided by (*name organisation*) today.

B1) What was the main purpose of your/(*user's*) use of (*name organisation*) today?

note in full

B2) What is your/(*name)*'s difficulty?

note in full and probe - full description, onset, cause,

B3a) Do you know the medical diagnosis of this difficulty?: |yes| |no | *(if yes follow filter b)*

→- *if yes b)* What is the diagnosis?

(Diagnosis from records - office use only ______________________________)

TIME

READ: I now want to ask about the time that you have taken using this service today.

NOTE: *USE EITHER B4 AND B5 (IN HOME) OR B6 AND B7(IN CENTRE)*

IF IN USER'S HOME

B4) How long was the session today?: _____hours _____mins |dk| |NA|
(*probe - estimate, ask start time and finish time*)

B5a) Did you wait in especially for the session today?: |yes| |no | *(if yes follow filter b)*

→ *if yes* - b) How long did you spend waiting for the session today?: _____:_______

OR

IF SESSION NOT IN USER'S HOME (IE IN CENTRE ETC)

B6a) How long was the session today?: _____ hours_______ mins |dk| |NA|
(*probe - estimate, ask start time and finish time*)

b) What time did you leave home today (approx) _____:_______

c) What time will you expect to get home today? _____:_______

TOTAL TIME SPENT _____:_______ hours

USER COSTS

READ: Our study is interested in how much the services provided by (*name organisation*) cost to those using them. I would like to ask about your experience **TODAY**.

B7 to B10) When using *(name organisation)* **TODAY**, did you spend any money on the following things?

	a) Spend money? *circle one only*			b) How much?	c) If over R.X ask *"what for?"*
B7) Consultation	|yes|	|no |	|dk|	R_____.________	__________________
B8) Medicines (*inc. purchased prescriptions*)	|yes|	|no |	|dk|	R_____.________	__________________
B9) Equipment	|yes|	|no |	|dk|	R_____.________	__________________
B10)Other	|yes|	|no |	|dk|	R_____.________	__________________

READ: I now want to ask about other costs related to your experience today.

TRANSPORT COSTS: IF THE USER HAS TRAVELLED TO THE SESSION

B11) How did you/the user travel here today?:

Tick one. For mixture tick one covering largest part of journey. Record all expenditure on transport below.

| | private car
| | taxi/rickshaw
| | public bus → did he/she use bus pass? | |
| | school bus
| | bicycle
| | walk
| | other (what?) ________________
| | NOT APPLICABLE

B12a)	(**COST FOR USER**) Did you spend any money on transport (for the user?):	|yes|	|no |	*(if yes follow filter b)*
→	b) How much on the way here?	R______._______		
→	c) How much on way home (*estimate*)?	R.______._______		
B13a)	(**COST FOR ACCOMPANIER**) Did you spend any money on transport for the accompanying person (*if applicable*)?:	|yes|	|no |	*(if yes follow filter b)*
→	b) How much on the way here?	R______._______		
→	c) How much on way home?	R.______._______		

COST OF WORK MISSED - FOR ALL:
TO THE USER:

B14a)	If you hadn't had this session now, would you normally have worked and earned money?	|yes|	|no |	|*dk*| *(if yes follow filter b)*
→	b) How much money would you have earned in the time spent using this service?	R.______._______		

TO ACCOMPANYING PERSON/PEOPLE (IF APPLICABLE):

B15) If you hadn't had this session today, what would you have been doing? ______________________________

B16a) Would you have earned money? |yes| |no | |dk| *(if yes follow filter b)*

→ b) How much money would you have earned in the time spent using the service? R.______.______

TOTAL EARNINGS LOST R.______.______

GRAND TOTAL **R**______.______

Section C - STAFF ATTITUDES

C1) Who/which worker(s) did you see today? (*name*): ______________________________

C2) What did (*name worker*) do today?: *write:*

C3a) Did the worker explain what he/she was doing in the session?: |yes| |no | |dk| *(if yes follow filter b)*

→b) What did he/she tell you? *write:*

C4a) Were ***you*** able to say all that ***you*** wanted to say today?: |yes| |no | |dk| *(if no follow filter b)*

if no→ b) Why was this?: *write:*

C5) Did you feel that the worker listened to *you* today?: |yes| |no | |dk|

Section D -RANGE OF SERVICES USED

D1) How long have you been using this (*name organisation*)?: |__|__| years |__|__| months

D2) How many times have you had contact with the (*name organisation*) in the last month (including this time)?: *tick one only*
☐ once
☐ 4 or less
☐ more than 4 times

D3) Where did these [name number] contacts take place? (use probes)
a) home |__|__|
b) at centre in community |__|__|
c) at (name organisation)'s centre |__|__|
d) other (where?) |__|__|
TOTAL |__|__|

D4a) Has (*name organisation*) been of use to you?: |yes| |no | |dk| *(if yes follow filter b)*

→ b) What are the two most important ways in which (*name organisation*) has been of use to you? (NOTE): **NOTE**: ***do not*** *offer suggestions as probes*

bi)	
bii)	

D5) **READ** : If you think of your experience before you had contact with (name organisation), how does the quality of your / (*name user*)'s life NOW compare with THEN:

Is the quality of your life: a) **THE SAME** now as it was then

b) **WORSE** now than it was then

READ ALL: c) **BETTER** now than it was then

d) |don't know|

Section E - EDUCATION OF SERVICE USER

NB/ SECTIONS E AND F FOCUS ON THE USER ONLY

E1a) Have *you/name user* ever attended school?: |yes| |no | (*if yes follow filter b; if no go to Q.E.2 below)*

→ b) Do *you/name user* attend school now? |yes| |no | |NA|

→ c) What is the highest grade class that *you/user* reached? (*circle one only)*:

| 1 | | 2 | | 3 | | 4 | | 5 | | 6 | | 7 | | 8 | | 9 | |10| |higher| |NA|

→ d) What type of school do/did *you/user* attend? (*tick for primary and/or secondary as appropriate*):

	PRIMARY SCHOOL	**SECONDARY SCHOOL**
tick one only for		| *special school*		| *special school*
for primary and		| *mainstream school*		| *mainstream school*
one only for secondary		|*other (what?)* ___________		|*other (what?)* ___________
as appropriate	|NA|	|NA|

→ e) Has (*name organisation*) helped you/user in any way with schooling?: |yes| |no | |NA|

E2a) Have *you/user* ever had any help with literacy? |yes| |no | |NA| (*yes follow filter b)*

→ b) Has (*name organisation*) helped *you/user* in any way with literacy?: |yes| |no | |NA|

Section F - TRAINING AND EMPLOYMENT

F1) EMPLOYMENT OF SERVICE USER

F1a) Do *you/user* work to earn money?: |yes| |no | (*if yes follow filter b; if no go to Q.F2)*

→ b) What work do *you/user* do?: ______________________________

→ c) Is this *work* only for disabled people?: |yes| |no | |NA|

→ d) Is this *workplace* only for disabled people?: |yes| |no | |*NA*|

→ e) How did *you/user* get this work?: ______________________________

→ f) Did (*name organisation*) assist *you/user* in any way in getting this work?: |yes| |no | |*NA*|

F2) TRAINING OF SERVICE USER

F2a) Do/have *you/user* ever received training to do work?: |yes| |no | (*if yes follow filter b; if no go to Q.F3 below)*

→ b) Are *you/user* training to do work now? |yes| |no | |*NA*|

→ c) What work are/were *you/user* training to do? ______________________________

→ d) Where do/did you/user do this training?:______________________________

→ e) Is/was this ***training*** only for disabled people?: |yes| |no | |*NA*|

→ f) Is/was the training ***at a place*** only for disabled people?: |yes| |no | |*NA*|

→ g) Did (*name organisation*) assist you in any way in getting this training?: |yes| |no | |*NA*|

FOR ALL F3) What work would *you/user* ***like*** to do?: ______________________________

Section G - <u>CONVERGENCE</u>

READ: I now want to ask you (*name individual*) about any other services and organisations that you/(*user's name)* have used in relation to your difficulty in (*give appropriate functional description*).

(nb/ read the question for each of the four categories in turn and follow questions a, b, c, and d.)

IF YES -

c) Did (*name organisation)* assist you in using this?;

a) y/n

b) What?:

(*write*)

Circle one only

G1) Have you used any other MEDICAL rehabilitation services/organisations to help with this difficulty? |yes| |no |
______________________________ |yes| |no |
______________________________ |yes| |no |
______________________________ |yes| |no |

G2) Have you used any other EDUCATION related services/organisations to help with this difficulty? |yes| |no |
______________________________ |yes| |no |
______________________________ |yes| |no |

G3) Have you used any other EMPLOYMENT related services/organisations to help with this difficulty? |yes| |no |
______________________________ |yes| |no |
______________________________ |yes| |no |

G4) Have you used any other WELFARE related services/ organisations to help with this difficulty? |yes| |no |
______________________________ |yes| |no |
______________________________ |yes| |no |

Section H - <u>PARTICIPATION</u>

***NOTE**: Ask all questions in this section about the service user and the accompanying person in turn, when appropriate:*

H1) SERVICE USER:

Apart from using the services provided by (*name organisation*), are you involved in any other way with the organisation? |yes| |no | *(if yes follow filter below)*

→*b)* How?

H2) ACCOMPANIER *(IF APPLICABLE)*

Apart from using the services provided by (*name organisation*), are you involved in any other way with the organisation? |yes| |no | *(if yes follow filter below)*

→*b)* How?

H3) SERVICE USER:

a) Are you a member of any groups within the organisation?: |yes| |no | *(if yes follow filter b)*

→*if yes* b) Whatgroup?:___________________

→*if no* - c) Do you know of any such groups?: |*yes*| |*no* | |*NA*| *(if yes follow filter d)*

→*if yes* - d) Why don't you belong to this/these group(s):

d)

H4) ACCOMPANIER *(IF APPLICABLE)*

a) Are you a member of any groups within the organisation?: |*yes*| |*no* | *(if yes follow filter b)*

→*if yes* - b) What group?:___________________

→*if no* - c) Do you know of any such groups?: |*yes*| |*no* | |*NA*| *(if yes follow filter d)*

→*if yes* - d) Why don't you belong to this/these group(s):

d)

APPENDIX 5: EVALUATION FOCUS GROUP DISCUSSION PROTOCOLS

4a) FGD protocol for persons with disabilities and family members (service users)

This protocol was adapted according to whether it was used with groups of persons with disabilities, or with family members. The core issues remained the same.

1) SERVICES AND SERVICE USE

a) *Overview of the service*

What services and activities do you use?
- How long have you been connected with the organisation?
- What other things are available at the organisation that you don't use (list all)
- What does the organisation do best? What does it do least well?
- Where do the services that you use take place?
- What is good about this/bad about this?
- Where would services best be provided?
- Do you think that you will always belong to/ use the organisation? *Probe why?/ not?*

What are the staff like in the organisation?
- What is the role of staff?
- How do they treat you? How do they make you feel?
- What are the best things? What are the least good things?
- What kind of people make the best staff in an organisation like this?
- What kind of people make less good staff?
- What are the important features of both?
- Is there a difference in the way that services are provided between staff who are persons with disabilities, the relatives of persons with disabilities, and those who have no such link?

How do the organisation, staff, and the services make you feel?

b) *Daily service use*

Participants to describe experience of using the organisation's service on a normal day
- What are the major features, and activities through the day other activities, child care for other children, getting ready, transport, waiting, activities etc, transport home

What are the costs of using services and activities organised by the organisation?
- money costs (direct costs), other costs (offer probes of: time, effort, what else would you have been doing)

c) Coverage and convergence

What kind of people use the organisation? What kind of people do not?
- Do you know people who could/should but don't use the organisation?
- *Discuss the reasons for use and non-use (think of barriers to use - why do some people not use the organisation*

What other services for medical rehabilitation, welfare, education, training and employment do/have the participants used or visited.
- Why did they use others? Do they still use this? What do they get? How are they different to the organisation? How do these services compare with the organisation? Why do some people choose to use other services instead?

How does the organisation compare with other services?
- Do any others do anything better than the organisation?

e) Participation

Apart from service use, in what other ways do service users and their families take part in the organisation?
- Do the users of the organisation have a role in the way that the organisation runs? What is this role?
- Do persons with disabilities and their families have any responsibility for the running of activities by the organisation?
- Who has the most say: persons with disabilities or their parents?

Who *does* decide the policy and objectives of the organisation?
- Should the users of such an organisation have a role in this?

Are there any groups for users and their families to join?

List groups and enter on cards.
Who has any experience of these? What is the motivation? Who does not join? Why? etc etc.
Who generally does this/ who does not do this? Why?
Are there different roles for different users/user's families? What is the difference? Who does/should do what?

Where do the organisation get the money from which pays for the services?

f) ***Advocacy, self advocacy and disability as a socio-political issue***

What does 'rights for persons with disabilities' mean?
Rights for what?
Have Rights changed in recent times? How have they changed? How could they change in the future? How might this happen? What can the organisation do about this? Are there factors which unify persons with disabilities. Are there factors which divide them?

What does the organisation mean for persons with disabilities in terms of their rights?
Does the organisation encourage or help persons with disabilities them to attain rights? How? Do persons with disabilities come together at the organisation? is this important, does organisation do anything about this, are groups encouraged, what is missing in groups. Do you know about the Disability Bill? What do you know? Are there any groups of persons with disabilities in the organisation? Do they discuss rights etc?

2) LIFE IN THE COMMUNITY

What is life like for persons with disabilities in your community?
What are the expectations in life of persons with disabilities in your community?

What are the most important factors in the quality of life of persons with disabilities?
What are the important factors in the quality of life of non-persons with disabilities? Are there any similarities? What are the differences?

What are the barriers to improved quality of life for persons with disabilities in your community?
What might make life better for persons with disabilities (apart from money)
Are there differences in the quality of life in urban communities with those in rural communities? How do they differ? What causes these differences?

What effects do the rest of the urban community have on persons with disabilities?
How do they treat persons with disabilities? How do you feel about this? Does the way people treat persons with disabilities vary? How does it vary? What support is available within the community?

What could be changed in the community to make life easier
What is the most important thing?

3) QUALITY OF LIFE, AND THE ORGANISATION

What the organisation has meant for you/your child; you (parent); the rest of the family (as applicable)
What has the organisation meant for the life of your family? Give areas - social, physical, economic,
Life before and after contact with the organisation, quality of life, how you feel about yourself, confidence, self perception, life expectations
What were your/their expectations in life before contact with the organisation? ...and now? And what are your/their future aspirations?

What has the organisation meant for the quality of life of the persons with disabilities who use its services?
Has the organisation meant anything for the quality of life of persons with disabilities in your community?
Do non-persons with disabilities in you community know of the existence of the organisation?
Do they know anything about the work of the organisation?
What kind of actions/messages do the people receive?
What does this do? Does the contact change them in any way?

4b) FGD protocol staff of partner organisations

1) SERVICE PROVISION AND SERVICE DELIVERY

What are the aims of the organisation?
  What is the organisation's role in lives of disabled people?
  What is the underlying motivation behind the organisation and the services that it offers? (*probe* - empowerment, development, rights)
What are the best aspects of the organisation? What does it do best?
What are the least good aspects of the organisation? What does it do least well
  What did the organisation do at the beginning? What does the organisation do now? What will it do in the future? What does this depend on?
  Are there things that the organisation should not get into?
  Are there things that the organisation should stop doing at any point?
What aspects of the lives of disabled people in this city requires the most urgent attention?

a) Coverage

Does the organisation offer a service to everyone in [the city] who needs it?
Who is served? Who is not served?
  List those who are/ are not. What are the differences? *List* determinants of each. Could the coverage (the numbers of people served) be increased? How could this be achieved? Should the coverage be increased? Where is the limit?
Is the organisation used by people living in the urban slums?
  If not why not? Do you think that the organisation should provide services for those in urban slums? Discuss. Is there any future commitment for extending the organisation's services to serve more low income disabled people?

b) Service approach

What is the relationship between the organisation and the Government of India?
  What is the role of the Government in the organisation? Does the Government have a responsibility in the services provided by the organisation?
Where is the best place to deliver the services that the organisation provides?
  What are the advantages of home and centre based work? Which works best?
  What do you think about he move from centre to community services that some are embracing? What are the ideas behind it?

c) Staff attitudes, participation, advocacy

What drew you to this work in the first place?
Are staff who are disabled people different in their approach to those who are non-disabled?
  Are staff with disabled relatives different to staff without?
What is the role of disabled people in the organisation?
  How did the disabled people in the staff come to work at the organisation
  What were they doing before they came to the organisation? What do they do at the organisation?
  What has the organisation done for them?

What does participation mean? ... what does it mean at the organisation?
  ...participation in the decision making process? Any future developments?
  Who makes the policy decisions at the organisation? What is the role of staff in decision making and policy formulation? Have you had any say in policy?
Where does the organisation get the funds to pay for its services?
  How much is the annual budget? Will these funds always be available?
  What are the barriers to greater participation of disabled people?

What does 'Rights for disabled people' mean? *(rights to what?)*
  Who should work for the rights of disabled people?
  What does 'advocacy mean?
  What does the organisation do about this? What should it do?
Does the organisation encourage the persons with disabilities who use the service to meet together?
  And without the presence of members of staff or their parents?

APPENDIX 6: TRACER STUDY METHOD

The method developed for the evaluation of medical rehabilitation in the UCBR project is a based on the tracer approach and was developed by an interdisciplinary team from India and the UK with expertise in CBR and social research.

1.1. Selecting people and the 'tracer conditions' for study

The functional difficulties used as indicators are listed in table A1. 'Moving difficulty' was divided into two diagnostic categories since 'rehabilitation' in the two conditions is not comparable.

Table A1: The selected tracer conditions.

1. Moving difficulty - cerebral palsy
2. Moving difficulty - polio
3. Seeing difficulty
4. Learning difficulty
5. Communication difficulty
6. Epilepsy

In each organisation, four persons with disabilities with each selected tracer condition using the service were selected to assess medical rehabilitation quality where possible. These ideally included a man; a woman; a boy; and a girl (both under 14 years). Thus, the maximum number of persons with disabilities selected was 24, assuming that all six tracer conditions were represented by the users of the organisation. All of those selected came from low income households. They were identified from user records, from data from a questionnaire of organisation users, and from information from organisation staff. At the point of service use they were asked if they would permit their service session to be observed by the fieldworker, and would respond to subsequent questions.

1.2 The tracer methods

Methods were developed with which to assess different aspects of medical rehabilitation;

- **A.** Management of rehabilitation using goals and concordance of goals
- **B.** Quality of interpersonal process
- **C.** Daily living skills were being addressed where needed
- **D.** Appropriate education or workplan
- **E.** Impairment specific minimum technical standards of service provision.

The methods directly addressing service quality focused on the observation of a service use 'session' that took place on a single day. This information was complemented with available data from records and from interviewing the disabled person.

Table A2: The methods used to make up the 'Tracer File' for each individual.

A	**Management And Goals ('Structure')**	
	Questions to service provider relating to management goals.	*single method for all users*
	Examination of records for existence and assessment of management goals.	*single method for all users*
	Summary and comparison of i) service provider's and service user's goals, and ii) service provider's and recorded goals.	*single method for all users*
B	**Interpersonal Process** Observation of service session based on explicit standards.	*single method for all users*
C	**Daily living skills**	*single method for all users*
D	**Education or workplan**	*single method for all users*
E	**Minimum Technical standards** Based on minimum standards for each condition, and the most appropriate approach for each (observation, questions to service provider; to user; to carer).	*specific standards for each tracer condition*
	Additional Information <u>Exit interview with user</u> - including service use, socio-economic details, daily living skills, users' own goals. <u>In-Depth interview with user</u> - qualitative information on quality of life, life experience, social integration, experience of service over time etc.	*single method for all users* *single method for all users*

Forms outlining each method and recording data were collected together in a 'tracer file' and completed with people representing the tracer conditions. Each complete file gives a detailed and in-depth description of the disabled person and the quality of his/her service use. The method was piloted with persons with disabilities who use a community disability service in West Bengal. A tracer file was completed for individuals from all of the tracer groups. In the evaluation proper, the fieldworker applied the methods alone. The organisations under evaluation were not given access to the contents of the tracer files before evaluation to avoid the risk of the organisations moulding service delivery sessions around these minimum standards.

A Management - rehabilitation goals

With reference to the use of goals for management of rehabilitation, quality was defined in three dimensions:

1. Goals should be functional.
2. Goals should be set through consultation between the service provider and the disabled person, and when appropriate the parents or other carer.
3. Goals and the intended time scale should be recorded for future reference.

For each tracer file, the fieldworker recorded three types of goal (if they were available).

A. Service provider's goals: After the observation of the service interaction 'session', the service provider was asked to describe any goals that she/he had for that service user.
B. Recorded goals: Secondly, if user records were available, they were examined and any written goals recorded.
C. User's goals: In the exit interview, the disabled person or their carer was asked if they had any rehabilitation goals for the next six months. They were also asked if they knew of any goals that the service organisation had for their development. These were also recorded.

In each category, up to three goals were recorded. The service provider's stated and recorded goals were examined by a CBR consultant to assess whether they were functional in light of the rest of the information. In a service in which rehabilitation is framed around functional goals, and these are a) planned through consultation between the disabled person and the service provider and b) recorded for future reference, goals from these three sources would be expected to converge. Convergence should be expected if goals are to be of any use in the appropriate management of rehabilitation. For each tracer file, the UCBR team compared goals A with goals B; and goals A with goals C and, after discussion, decided if there was any convergence. As with the technical minimum standards, a pass or fail approach was taken. Any convergence was an indicator of good practice. This method is developed from Sebeh (1996)[14].

B Interpersonal quality

A list of 'good practices' was developed on which the quality of interpersonal processes between service providers and service users in community based disability services could be assessed. The list was broken down into four parts; i) management; ii) respect; iii) communication and listening; and iv) transfer of skills. All four involved assessments made by the fieldworker while observing the session. For the latter three, observations were supplemented with data drawn from an exit interview giving the user's perspective of the interpersonal aspects of the session.

Unlike the pass: fail assessment of technical standards, the assessment of interpersonal quality was scored on a continuum, with one mark given for each 'good practice' recorded, and these added together. The outcome score for this section was derived by dividing this score by the total possible score. Items that were deemed 'not applicable' for that interaction did not negatively affect the outcome score. Again, the fieldworker was advised to use the 'not applicable' option judiciously.

C Daily Living skills

Service providers were asked if they were addressing any needs for daily living skills. Their responses were recorded and checked with responses to a similar question on needs and activities to the persons with disabilities and their families (see exit interview below).

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[14] Sebeh A.G. (1996) *Evaluation of CBR for Disabled Children in urban slums in Egypt.* Unpublished PhD thesis, University of London.

D Appropriate Education or work plan

Service providers, persons with disabilities and their families were asked whether any plan for appropriate plan for learning or earning money was in place.

E Assessing technical quality by minimum standards

The methods for assessment of technical quality is based around the *minimum* technical standards. For each tracer condition, a list of common rehabilitation inputs was drawn up. The importance of each one in terms of functional rehabilitation, and in the context of low income urban communities in India, was considered. Those that were not functional, or were presently inappropriate in low income communities in India were discarded. For example, referral to a specialist neurologist on diagnosis of epilepsy is the norm in the UK, but in India this is unrealisable for poor people. After discussion, and with independent inputs from persons with disabilities and experts on rehabilitation for specific impairments, a list of minimum technical standards was drawn up for each condition. Some of those chosen may not be recognised by a general audience as strictly 'medical' rehabilitation issues, but it was felt that these should be included as essential minimum standards in holistic, functional, and appropriate rehabilitation in urban India. For example, the minimum standards for people with learning difficulties relate to daily living skills. Different minimum standards were drawn up for children and adults.

A means of assessing each of the minimum standards was developed. This usually involved observation of a service interaction, and questions to user and provider, but where this was not appropriate, other methods including examination of records and material resources were used. For each tracer condition, a printed form outlined the minimum standards and the methods by which to assess them. For each standard, the fieldworker indicated whether or not it had been passed, and made detailed notes to support this assessment.

Evaluation using the minimum technical standards is scored on an 'all or nothing' basis. Service sessions either satisfy *all* of the appropriate minimum standards and pass on the basis of technical quality, or fail (whether one, or all of the minimum standards are not met). If any standard is deemed not to be applicable for that individual, it is not applied and has no bearing on outcome. For example, a mobile individual with cerebral palsy might not require advice on sitting to enhance function. This standard would be left out. This was left up to the judgement of the fieldworker, but notes were taken to explain the decision. The fieldworker discussed each disabled person's file with the UCBR team and the session assessed as having achieved or failed the minimum technical standards. For an organisation, the outcomes can be presented in terms of 'achieved minimum standards for 12 users, but failed for 8', or 'achieved minimum standards for all users with moving difficulties, but failed for seeing difficulty'.

The only adaptation to the method made after application has been the presentation of the results of technical quality of services for cerebral palsy, where the recording of contractures was found to be unpracticed throughout the organisations evaluated. This resulted in an artificially low score for those services focusing on the needs of this group. Therefore scores have been presented with and without this minimum standard included.

1.3 Additional information

Exit interview: The quality assessment tools applied during the service session were followed by an exit interview with the service user. This schedule addressed the user's inputs in the evaluation of quality. The schedule recorded:

1. The user's rehabilitation needs for four daily living skills (feeding, washing, dressing and toiletting - if applicable).
2. The user's educational and/or workplan
3. The user's rehabilitation goals
4. The user's perception of the quality of the interpersonal process

This data was added to the quality assessment data where appropriate. The schedule also collected background socio-economic data about the disabled person and his/her household.

In-Depth interview: At a later date, an in-depth interview was conducted by the same fieldworker with the disabled person (and accompanier where necessary). It collected detailed qualitative information on the user's service use, wider perceptions of the service organisation, and the user's quality of life.