BANGALORE COMMUNITY STUDY

Urban Community Based Rehabilitation Project

Final report

Urban Community Based Rehabilitation (UCBR) Project - India

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

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To be circulated to
CHC team for information
and comments/suggestions
if any.

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i Executive summary

1. Background to the UCBR Project: With rapid urbanisation and the growth of urban poor communities, the Indian Ministry of Welfare is investigating 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. The UCBR Project has undertaken community studies in three cities to investigate the expressed needs of persons with disabilities and their families from low income communities, and evaluated eight representative service providers in relation to these needs. This is the report of the Bangalore community study.

2. Aims and methods of the community study: The aims of the community study were to explore: i) the expressed needs and experiences of persons with disabilities and their families in low income communities of Bangalore and ii) their experiences of existing services in relation to these needs. Complementary qualitative and quantitative methods were applied. These included a questionnaire interview, and additional discussion, with 200 persons with disabilities and their families in a random sample of low income communities across the city, plus eight Focus Group Discussions (FGDs).

3. Findings of the Bangalore community study:

3.1 The expressed needs of persons with disabilities and their families: The priority need was for work and income. This applied for both persons with disabilities and their family members. The next priority need was education. For the majority, and with increasing age, medical needs were less prioritised.

3.2 Experiences of work and income

i. 25% of persons with disabilities over the age of 15 did paid work. Limited available data with which to compare the study's findings suggests that adults with disabilities were less likely to be in paid work than adults in the urban population in general.

ii. For persons with disabilities in Bangalore who were working, most opportunities had been found within their own communities, and accessed through local social contacts such as family, neighbours, and friends. The majority of skills training for persons with disabilities was informal and occured in the workplace.

iii. Experience of vocational training for persons with disabilities was very limited, as was access to government welfare in the form of pensions, special employment opportunities, and loans.

iv. Support for work opportunities, such as loans, for the family members of persons with disabilities, particularly persons with severe and multiple impairments, was not practically available.

3.3 Experiences of education:

i. Nearly 50% of the person with disabilities interviewed had never been to school. Comparison with general data on school registration suggests that persons with disabilities are less likely to go to school than the population at large.

ii. The coverage of children with disabilities by mainstream schools out numbered that of special schools by nine to one. The number of special schools was small, and they were located far from most people's homes, thus transport and other associated costs were great and tended to exclude poor people.

3.4 Experiences of medical rehabilitation:

i. Despite the prioritised need for income and education, virtually the only rehabilitation services experienced by persons with disabilities from low income communities were medical. 85.5%

of those interviewed had used a medical service in relation to their difficulty, mostly government hospitals.

ii. Less than 10% of persons with disabilities encountered during the study had used rehabilitation-oriented NGO services.

iii. Medical rehabilitation services did not meet needs for medical rehabilitation. Interventions for those with moving difficulties had a questionable impact on mobility. For example, many aids were issues but not used, and persons with disabilities chose to manage their own mobility without aids. This prompts questions about the appropriateness of interventions, and their cost effectiveness.

iv. Services for those with severe and multiple disabilities were arranged for diagnosis, mobility, and prevention of further impairments. They did not address the day-to-day needs, particularly as these needs change across a person's life span. They did not address functional self management skills, which would help persons with disabilities gain more control over their lives, and would allow their family members to do other things. Persons with disabilities and their families reported that medical services do not provide emotional or social support, or appropriate information about impairment and future expectations.

v. The centre-based delivery of medical rehabilitation services caused considerable structural and economic barriers, particularly for poor people. Like special schools, they were a considerable distance from most communities, and associated barriers related to cost, time, and practical difficulties of transport, which were experienced by all groups of persons with disabilities, particularly when frequent attendance was advised by service providers. Another significant barrier to centre-based services was the cost of paid work missed while attending services. These, and direct service costs, exacerbated the poverty of families of persons with disabilities in low income communities

vi. Persons with disabilities described considerable attitudinal barriers to medical rehabilitation institutions; some service providers are unsympathetic and lack respect for poor people.

vii. Use of medical rehabilitation services by poor families often ended soon after it had begun. After this, the only source of support for most persons with disabilities was their own family and home community.

3.5 Experiences of community life:

i. Although persons with disabilities may have suffered negative attitudes in home and community, the greatest, and in many cases, the only support available to them was from family and in community.

ii. The needs of many persons with disabilities, and other community members such as the old and the young, were not included in the planning or building of community infrastructure such as sanitation and water supply and thus they had difficulty in using them.

3.6 Disability and poverty: it is known that prevalence of impairments is greater in low income groups. This study found evidence suggesting that disability also causes increasing poverty through reduced opportunities for paid work for persons with disabilities and families, and the costs of rehabilitation.

4. Conclusion: Persons with disabilities and their families in low income urban communities prioritised needs for income, education, ahead of medical rehabilitation, yet the vast majority of service provision attempted to address this least expressed need. The greatest support for real needs was found within families, and in 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 communities, and was not organised to be accessible to poor people.

ii Introduction

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 develop 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 report of the Bangalore Community Study is part of this process.

iii Glossary

BUPP	Bangalore Poverty Alleviation Project
FGDs	Focus Group Discussions
KSFC	Karnataka State Finance Corporation
NIMHANS	National Institute for Mental Health and Neuro Science
UBSP	Urban Basic Services Programme

SECTION 1 INTRODUCTION

1.1 Aims

The aim of the Urban Community Based Rehabilitation Project's Community Study in Bangalore is to explore:

i. the expressed needs and experiences of persons with disabilities and their families in low income communities of Bangalore.
ii. their experiences of existing services in relation to these needs.

1.2 Methods

Complementary quantitative and qualitative methods were used. Throughout the community study and related organisation evaluations, persons with disabilities were classified according to their difficulties[1]. This was the most suitable approach given the focus on practical needs, and also appropriate to the community study's use of social scientist fieldworkers and key informants.

1.2.1 Quantitative method

The UCBR study used a questionnaire approach to draw a representative picture of the socio-cultural and socio-economic situation of persons with disabilities in low income communities and their use of services in relation to their difficulties.

The needs of persons with disabilities were left to the qualitative methods as addressing needs during a relatively short quantitative interview would create expectations which could not be met by the UCBR Project. Therefore, there is no quantification of needs. Qualitative discussion of needs was recorded in household interviews and FGDs.

The UCBR questionnaire did not aim to estimate the prevalence of impairments in low income communities. The proportion of the population who are persons with disabilities, and prevalence of impairments in India has been estimated in previous studies[2]. Surveys to identify persons with disabilities, or establish the prevalence of different impairments have been carried out in the past but are costly, time consuming, and inaccurate and have not researched the needs of persons with disabilities have not been researched, and little improvement in the situation has resulted from them[3]. It was interesting to find that prevalence surveys were also rejected persons with disabilities and their families in low income communities in Bangalore:

> "The Urban Basic Service Programme did a survey on disability. But they only questioned about the disability - like which leg - and nothing else. They came during the elections and promised many things and nothing happens."
>
> *woman with moving difficulty, FGD4.6*

The sample size for the community study was calculated using Epiinfo's 'statcalc' statistical calculator. Using an estimated slum population size of 3,000,000 a sample size of 198 was 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 was necessary given the expected diversity of the population in low income communities and the resources available for the community study.

The sample used a random cluster sample of slums from comprehensive list of slums in Bangalore city. 20 clusters were sampled from a list of low income communities in the Bangalore Municipal area. The list was compiled in August 1996 using inventories of low income

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

[2] For examples see: Pandey R.S. and Advani L. (1995). *Perspectives in Disability and Rehabilitation.* Vikas Publishing House: New Delhi.

[3] World Health Organisation (1984). 'Drop that census'. *World Health, the Magazine of the World Health Organisation* (May issue: Rehabilitation for all). p.4

communities and estimates of the populations of each. The core of this list came from a survey by Bangalore Urban Planning Project (1991-92) of 444 slums, with appropriate additions from the Karnataka Slum Clearance Board's (1995) list of 298 slums. 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:

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

For each of the 21 (see appendix 1), a sample size proportional to the communities' population size was calculated.

One the sample was drawn up, the method considered to be the most cost effective means of locating persons with disabilities was by seeking key informants and asking them to help. Fieldworkers visited each community and sought key informants. They described the aims of the community study, described the type of people who the study planned to interview, and asked them to help find people to be interviewed. The types of key informant used to locate persons with disabilities are listed in appendix 2. This method proved time consuming; each fieldworker could locate and interview a maximum of 4 people per day. This indicated that FGDs might also prove difficult to organise as a number of persons with disabilities or family members would have to be recruited and motivated to come to a meeting. Therefore, to maximise opportunity for data collection, quantitative data collected in the questionnaire was complemented with qualitative notes.

Interviews were carried out in late 1996, by the Evaluation Officer and City Research Officer. Questionnaires were delivered in Tamil, Kannada, Telegu, and Hindi, as appropriate. The English version of the questionnaire is included in appendix 4. In all, 200 persons with disabilities and their families were interviewed. 10 were re-interviewed by another fieldworker to check the validity of the interview method. All those interviewed were offered information about appropriate services available to persons with disabilities in Bangalore.

1.2.2 Qualitative methods

Eight Focus Group Discussions (FGDs) were held in the community with persons with disabilities, and with their family members. The FGD plan is included in appendix 5. Participants were also divided according to gender and age groups. FGDS were organised with the assistance of community organisations and local NGO workers. The following FGDs held:

1. Women with disabilities, Koramangala.
2. Girls with disabilities, under 15 years old, Kamalanagar.
3. Boys with disabilities under 15 years old, Jalahalli
4. Men with moving difficulties over 15 years, Bapujinagar Layout
5. Mothers of children with disabilities, Koramangala.
6. Mothers of children with disabilities, Haleguddadahalli
7. Mothers of children with disabilities, Adugodi
8. Father of children with disabilities, Haleguddadahalli

1.2.3 Methods and presentation of data

Fieldworkers often had difficulties in speaking directly to persons with disabilities. In some cases this was because the fieldworker did not share a means of communication with the person with disability, for example those with speech and hearing difficulties, or non-verbal people with multiple difficulties. This was exacerbated by a tendency for children to be talked about by a parent, and for other family members to speak on behalf of adults with difficulties. This partly reflects difficulty in finding a quiet and private space for interviews. The fieldworkers stressed that they wanted to speak to the person with disability directly, but persons with disabilities tended to be disempowered by other family members who would assume a position of spokesperson on their behalf, even if they were easily able to communicate themselves. Of the 200 interviews undertaken, in 175 there was someone else present with the person with disability during the interview. 38 (19%) of the interviews were with the person with disability as the lone respondent, and 160 (80%) with an accompanying person. Of these 'accompanying' people, the majority described themselves as 'the usual carer'. Thus, the qualitative data has many contributions by the non-disabled family members of persons with disability. For reasons of simplicity, presentation of quantitative data uses the term "respondents" regardless of whether responses were made by persons with disabilities, carers, or both. This data was restricted to reporting factual, rather than perceptual information. Perceptions and feelings were explored through qualitative methods. All qualitative quotations are attributed to the individual.

Before all data collection, respondents' permission was sought for their comments to be used in reports to the Ministry of Welfare. They were assured that no material would be attributed to them by name. To assure anonymity, quotes used in this report are accompanied by a brief description of the speaker, and a code number. Qualitative data is presented in the form of direct quotations from persons with disabilities and their families. For brevity, only one example has been included to describe each issue raised: a single quote represents a number of similar statements about the issue described. Discussion of findings is structured around a question and answer approach. Difficulties in accessing services are analysed in terms of barriers. For simplicity, the symbol ⊗ has been used to indicate discussion of barriers.

1.3 Description of community study sample

Persons with disabilities and their families were interviewed in the sample survey and participated in FGDs.

1.3.1 Difficulty groups

The representation of different difficulty groups in the sample are described in table 1. These frequencies of difficulty groups are not intended to represent their relative prevalence in low income communities in Bangalore. Rather, they are listed here to describe the group of persons with disabilities and their families interviewed in the community study survey.

Table 1: distribution of difficulty groups in the community study

difficulty group	***freq***	***%***
moving difficulties - polio	65	32.5
moving difficulties -other	32	16.0
learning difficulty[4]	13	6.5
epilepsy	9	4.5
speech and hearing difficulties	19	9.5
multiple difficulties	54	27.0
seeing difficulties	8	4.0
Totals	200	

1.3.2 Age

The sample only included one person with disability over the age of 55.

Table 2: age distribution of persons with disabilities

age group	freq	%
1-5	35	17.5
5-10	53	26.5
11-15	47	23.5
16-25	35	17.5
26-55	29	14.5
>55	1	.5
Total	200	100

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[4] some of those described by key informants and families as having learning difficulties or 'mental retardation' were almost certainly mentally ill.

1.3.3 Gender

In Bangalore, males comprised 105 (52.5%) of the 200 interviewed. The two fieldworkers were instructed to interview male and female persons with disabilities. There was no relation between gender and the types of difficulty represented in the sample.

1.3.4 Language

47% of respondents live in households in which Tamil is the first language; 17% Kannada; 17% Telegu; and 15% Urdu.

1.3.5 Religion

77% of respondents live in Hindu households; 15.5% in Muslim, and 7.5% in Christian.

1.3.6 Caste

Of the 144 Hindu households, 132 (92%) described themselves as scheduled caste or tribe; 8 as other backward classes; and 16 forward caste. 7 did not know.

1.3.7 Socio-economic status

Given the accepted difficulty and inaccuracy of addressing socio-economic status in quantitative interviews through questions about household income, proxy indicators were used to indicate household socio-economic status. The first indicator used was housing type. Pukka houses are defined by concrete roof; semi-pukka by asbestos roofs; semi-kutcha by tiled roof; and kutcha by mud walls. The second socio-economic indicator used was the occupation of the household head.

Table 3: socio-economic classification by housing materials

Housing classification	*freq*	*%*
pukka	30	15.0
semi pukka	75	37.5
semi kutcha	19	9.5
kutcha	76	38.0

127 of the 200 (64%) own the houses in which they live; 59 (29.5%) rent. 13 enjoy free occupation. The second indicator was the occupation of household heads:

Table 4: socio-economic classification by occupation of household head

job type of household head	*freq*	*%*	*valid %*
Unskilled labour	97	48.5	53.9
Skilled labour/craft	36	18.0	20.0
Petty business	26	13.0	14.4
Machinery operator	6	3.0	3.3
Clerical	2	1.0	1.1
Government employee	6	3.0	3.3
Business	1	.5	.6
Pension	4	2.0	2.2
Other requiring higher education	2	1.0	1.1
Missing	*20*	*10.0*	
Totals	*200*	*100*	

As data is missing for 20 of the respondents due to fieldworker error, the percentage excluding the missing data has been included in the last column. 11% of the persons with disabilities lived in households headed by a woman.

SECTION 2 Study findings: the needs and experiences of persons with disabilities and their families in low income communities in Bangalore

2.1 Introduction: summary of needs

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

1. work and income
2. education
3. medical rehabilitation

Needs varied according to individuals' specific difficulties and circumstances. All can be related to the common themes of persons with disabilities and their families i) gaining some economic security, ii) participating in the mainstream of life, and iii) increasing their control of their own lives. Needs relating to socio-economic security are shared by most households in low income communities of Bangalore. Household socio-economic and health needs may be more important and more immediate than those needs specific to a person's disability. The need for rehabilitation is less immediate than the need for food and basic health.

2.2 Needs and experiences of work and income

Work and income were the needs most commonly expressed by persons with disabilities and their families in low income communities:

> "[*persons with disabilities*] need a job, if they are employed in factory or office, or people who like to do their own business should get enough financial resources to start a business. Good skills training would help the disabled to find a job somewhere. There is a lack of financial support to do business either from individuals or from any organisations. If banks can give us loan without too much formality it will be very helpful... as far as I am concerned there is no other barrier apart from lack of financial support".
> *man 35, moving difficulties*

> "There is no income. If they can earn they can be independent"
> *mother of twins with moving difficulties. FGD4.8*

The need for employment was very clear. During interviews, some persons with disabilities and their families asked if the study fieldworker would help them get a job. This was particularly the case as the fieldworkers introduced the UCBR project as being on behalf of the Ministry of Welfare. There was, however, little insistence in this demand as unemployment was common for persons with disabilities and non-disabled alike. Many felt that the chance of getting employment for person with disabilities was very small. Work was a need expressed for both men and women:

> "We should support our husbands by earning, for the welfare of our children's futures... people tell me "how can you depend on your husband only? You should also work. Neighbours say "she is only fit for eating - not for doing any work".... it has been no use studying. It has not helped me, I can't walk far. I want something [*to do*] at home".
> *woman, 22, with moving difficulty. FGD1.1*

The following comment came from a woman who had had a stroke and been unable to continue her work in a garment factory:

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

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 this was the need for a job where they could sit down, perhaps in assembly for those with little education, or office work for those who had passed higher standards. However, office jobs were favoured by most unemployed people. Non-disabled family members who took part in discussions also wanted to find a job in an office, even if they were already supporting themselves through manual work. This competition reinforces the need for education if persons with disabilities are to find employment. Those with other difficulties also described the need for a job suited to their circumstances and abilities:

> "I can get about the community, but if I have to go outside the area then I need company. My parents support me. Now they are old and find it hard to manage. My brothers and sisters who are married live close by and support us by giving the essentials. I would like to work but will need someone to come and go with me. What work can I do?". *man, 33, with seeing difficulty. 188*

i) Job skills and vocational training A number of the adults with disabilities interviewed had completed education and work related training, mostly in private businesses. Others expressed the need to learn job skills as well as academic education to improve chances of employment.

> "Apart from money , a job or a training would definitely would help the persons with disabilities to make their lives better. Education is the most important need and job training is the next. I want to train my daughter to be financially independent but no one shows the way how to train her, her father is not bothered about doing anything for her".
> *mother of girl, 12, with speech and hearing difficulty.*

Some of those interviewed were still unemployed despite undergoing several types of training. They suggested that success of vocational training should be measured in terms of finding economically productive work.

ii) Loans for self employment: In the absence of work, some persons with disabilities and their families sought access to loans to provide start-up capital for small businesses:

> "...other women go to work as house maids and a few others roll *agarbathi* [*incense sticks*]. I cannot do either of these... I can do agarbathi work but I cannot do neat work, and the employer will pay only when the work is done neatly. There are other women who go for construction work and others are selling vegetables and fruits. They can do anything, even people with less disability can do something, but I cannot do anything. Jobs are needed for those who can do some work, and for other who want to do some business if capital is given they will be able make their living. I want to have cow and earn my living by selling the milk". *woman, 40, with seeing difficulty*

This feeling was also expressed at FGDs:

FGD women with disabilities - Koramangala

6	If I could be dropped to work and back home, or if I had enough money for an auto, then I could work outside. There is lots of scope for tailoring in this locality, we can easily earn about Rs.20 per day, but we need machines and don't have the funds... tailoring is easy for us since it does not involve outside work. People will come to us.
10	I would like to have a petty shop near my home, selling vegetables. I can't depend on my husband. He doesn't give me money regularly. I need Rs.500 to start this business.
4	I can use a sewing machine but don't have the money to buy one.

Other respondents recognised that people with severe and multiple impairments might never be in a position to work. They described a need for work for other family members:

> "Would I have applied if more money is given as pension? No I would not have applied. The families of the disabled should be given some loan to start some income generation programme so that they may use the income to support the persons with disabilities. This is for families who have people with have severe difficulties".
>
> *mother of man, 17, with learning difficulty and epilepsy.*

iii) Pensions: a few parents expressed a need for pensions:

FGD - Mothers of children with disabilities, Kamalanagar

Question:	*What do disabled people need?*
1	Anything. They need to have a way for living - a lifeline. Any job - for him to lead his own life. The government can give money - at least after our death - for them to continue their life. Parents will look after them while they are alive, but after that who will bother about their future? He can't work, the government should provide for him for his life time.
3	Money itself is required.
4	If the disabled can get about Rs.200 per month then it will help.

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

Of the 65 respondents over the age of 15, 16 (25%) reported that they are doing paid work. Two under the age of 15 were doing paid work. Half of all of those working are women.

There is a paucity of suitable data with which to compare this with work experience of the urban population at large in Bangalore. Available data is reported in absolute numbers of people working, and does not indicate the number not working. Various percentage estimates exist for urban India as a whole, although the nature of their calculation is unknown. One study under the Ministry of Urban Development[5], puts the total percentage of adults in urban India *without* any employment as 6.1% for males and 8.5% for females, and without any regular employment as 14.6% for males and 25% for females. The 1991 census reports figures for 'total main workers' as a percentage of the total population as 29.5 (48.59 for males and 8.13 for females) for urban India[6]. However, this population includes children. A comparative figure for persons with disabilities sampled in the Bangalore community study would be 8% (16 of 200). Concrete conclusion is impossible, but available data suggests that adults with disabilities are considerably less likely to be in paid work than the urban population in general.

The types of work done by the persons with disabilities interviewed are listed in appendix 3. None of these people were working in segregated jobs, or in segregated environments reserved for persons with disabilities. All were working in mainstream activities, in the economic life of low income communities. Only two of the respondents - a factory store keeper and a home tutor - were doing work which obviously depended on previous education. The other 16 jobs were manual. Four were involved in home-based production of *beedhi*, agrabati, and sewing; two were housemaids. The rest were unskilled workers including construction (2) and rubbish picking (2). There was no obvious relationship between the tendency for persons with disabilities to be doing paid work and socio-economic background of their household.

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[5] Mathur, O.P. (1993) *The impact of urbanisation on children*. Planning Commision, Ministry of Urban Development, Government of India and Unicef.

[6] Government of India (1991) Reported in the *Economic Review of 1996-97: Statistical appendix*, Government of West Bengal (1997).

> "He worked for 3 months at a book shop, but left because could not understand work to be done. If employers shouted, he would run away".
>
> *father of man, 22, learning difficulty and epilepsy.* 010

⊗ **lack of capital**: The need for loans expressed by person with disability is obviously an indicator of a lack of capital. As well as preventing the 'start up' of income generation, a lack of capital is a barrier to maximising earning for persons with disabilities who are working:

> "My wheel chair carries a board saying "stove repair" and I have made a living repairing kerosene stoves for the past year... I am not able to earn much as I don't have enough money to buy the spare parts. If I had money to buy spares I could earn Rs.100 a day."
>
> *man, 35, with moving difficulties from polio*

⊗ **gender**: In many households visited, women earned, or supplemented, income by rolling *agrabati*. This work is poorly paid and demanding on hands and eyes, but it is readily available and flexible, as other family members can assist when time allows. Some women and girls with disabilities who said that they were not doing paid work were helping doing some rolling for their mothers. This work is usually done by women but not by men. Although relations with the middle men (they were described as 'men') who supply the materials are reported to be exploitative, rolling *agarabati* has the advantage that little start up capital is not needed, unlike other home production such as tailoring.

⊗ **education:** There was no obvious relationship between education and finding work. For those of working age who had been educated to some degree, 28% were working. Of those with no education, 21% were working, but this difference is not significant and probably partly relates to the fact that those who have participated in education are more likely to be able to participate in work, regardless. Given the unskilled nature of jobs done by the person with disabilities interviewed, it appears that education is of little importance. However, the difficulties in work described for those with learning difficulties such as numeracy and 'work culture' are education-related barriers.

answer: barriers to work were described in relation to an individual's difficulty, lack of skills, lack of capital, and gender.

Question 2.2.4: is begging a common means of earning money?

Of the 200 persons with disabilities interviewed, none were begging. One man with severe moving difficulties had previously begged from the age of five years. He did not enjoy begging; he said it was degrading and he was now working as a stove repairer. Finding a job had been difficult. No welfare benefits were available, despite the police picking him up several times and telling him to stop begging as "the government provides for people like you".

answer: None of the 200 persons with disabilities interviewed were begging.

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

Only two of the 200 (1%) respondents reported that they had used any employment-related services for persons with disabilities; one had been to a vocational training centre for persons with disabilities, and one to a class for persons with disabilities in a mainstream vocational training centre. Both were now unemployed.

With regard to other services, 31 of the 200 (15.5%) reported that they had benefited from government welfare provision. These were; seven children with government scholarship; 25 people with pensions; and one with a place in a government remand hostel. One person reported having a bus pass. Relating access to welfare benefits to difficulty group is hard because of the small size of the sub-groups. The most striking feature of the distribution is that so few of those with multiple difficulties have got government welfare benefits. Although the severity of impairments cannot be generalised, this group were generally described as the least able to work and so would, as a group, seem most in need of pensions. Table 4 describes the distribution of welfare benefits in general across the difficulty groups.

Table 6: access to welfare benefits by difficulty group.

	Have welfare benefits?			
difficulty group	***yes***		***no***	
	freq	***%***	***freq***	***%***
moving difficulties - polio	13	20	52	80
moving difficulties - other	4	13	28	88
learning difficulty	1	8	12	92
epilepsy	0	0	9	100
speech and hearing difficulties	0	0	19	100
multiple difficulties	8	15	46	85
seeing difficulties	5	63	3	38
totals	***31***	***15.5***	***169***	***84.5***

Other variables such as gender, socio-economic status, and religion have no obvious relationship with access to welfare provisions in general, or pensions in particular. Those who had received pensions described them as a drop in the ocean of a household financial needs, but "better than nothing". One respondent, a 33 year old woman with a moving difficulty, reported that she was receiving a pension as well as doing paid work.

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answer: government welfare provisions had been received by 31 of the 200 interviewed. 25 adults had pensions, and 7 children had school scholarships. Coverage was limited and distribution did not appear to be equitable.

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

Several of the common barriers to application for a pension are described by these women:

FGD women with disabilities - Koramangala

5 I didn't get a pension although I tried.

6 unless we pay a bribe we don't get a pension.

9 I also tried to get a pension. The officers don't show any interest. So I did not pursue it.

3 Because I didn't know how to get a pension, I gave money to somebody I trusted to do it for me. I lost the money and nothing was done.

6 I have got a medical certificate about my disability.

3 I have tried giving forms at the Taluk office - they send me from pillar to post. They expect bribes... those who are educated are unable to get it. Then how can we get it?

6 UBSP did a survey on disability, but they only asked questions about the disability and nothing else. They come during the elections and promise many things, but nothing happens. Through UBSP social worker we came to know about pensions, but they could not tell us how to get them.

the money over. Some people were unwilling to discuss this, fearing that they would lose the benefit if they reported the postman to any authority:

> "I have been having trouble getting my pension, I do not get it regularly, and when I enquire at the Post Office the postman gets angry so I have to pay them money to pacify them". *woman, 43, with seeing difficulty. 199*

Respondents reported that this type of problem is common to all types of payment and benefits arriving by post. Problems with delivery may also be involved in the next barrier to receipt of pensions.

☹ **delivery is irregular, or suddenly stops:** Securing a pension did not mean that it would be issued on a regular or permanent basis:

> "I have been blind since the age of 7, following small pox. I get a government pension of Rs.75 per month and have been for 13 years, but it is very irregular - it comes about 5 times per year." *woman, 29, seeing difficulty. 100*

> "I had a pension for my son for 8 years. It was Rs.50 per month. But for the last six months no money has come. I don't know why. I feel why has this money stopped? At least we could eat porridge with it - now even this has stopped".
> *mother of man, 25, with learning and speaking difficulty. FGD1.1*

A few people knew that the pension had stopped because they had not renewed their application, but more had no idea why the pension had stopped coming.

answer: the numerous barriers to welfare services can be classified (with examples) as:

1. **environmental:** distance and physical access to government buildings
2. **economic:** alleged payment of bribes
3. **structural:** lack of information, complicated application, failure of delivery system
4. **attitudinal:** ignorance of government employees, demands for bribes by government officials and postal workers

2.3 Needs and experiences of education

After income, discussion with the persons with disabilities and their families focused on education. This was particularly the case for those with moving difficulties from polio and speech and hearing difficulties. Many already had some experience of school. In discussion, education was explicitly linked to increasing employment opportunities and socio-economic independence, especially as it was thought that persons with disabilities would be less able to find manual jobs than their non-disabled peers:

> "He attends a private school - it is Rs.75 per month, and Rs.100 for the auto there and back per month, and he also has private tuition. This is hard for us to afford, but we want him to be educated so that he can get a government job".
>
> *mother of boy, 8, moving difficulty, 030*

> "Education for him is the most important thing; the other children in the family are not being educated as it is not so important. He is a cripple so we send him to school, so that he can do something to pass time. The others don't need education. Also he can perhaps get a job if he studies, whereas the other children can work even otherwise".
>
> *father of boy, 8, moving difficulty. 051*

A few persons with disabilities stated the need for socio-economic assistance in education, but few knew of, or mentioned government scholarships:

> "I was educated in a private school for 4 years. I have applied to 2 or 3 ITI courses and am waiting the results. But what I really need is a loan to support my further studies. I want to work and be independent, and I feel that if organisations can give financial loan for studies it would help so that later she would be in a position to repay
>
> *woman, 17, with moving difficulty. 073*

Persons with disabilities with experience of school described barriers to both initial admission and daily attendance. Few suggested that school could be adjusted to meet the needs of children with disabilities, or that education is a right for all children including those with disabilities.

Question 2.3.1: what are persons with disabilities' experiences of 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, for practical reasons, examination of the coverage of education for persons with disabilities in Bangalore focuses on those over the age of 5, and on a theoretical current school age population of between the ages of 5 and 15.

Of those currently in school age (i.e. 5 to 15 years old inclusive) 10% (5 of the 25) had been to school, and one of these had now dropped out. For all those of five years or over, 62% (107 of 174) had attended school at some time. 66% of men and 58% of women had attended school (this difference is not statistically significant). These coverage figures do not indicate the quality or quantity of education. Some people reported that they had been to school and gained admission, but had not completed one year, or in some cases, one month. These crude coverage figures can be compared with estimates for average school attendance in urban Karnataka. In the year 1987-1988, estimates of school coverage for the 5 to 15 age group can be estimated as 74% for boys and 71% for girls[7]. Thus it appears that educational attendance is lower for persons with disabilities.

Table 7: school attendance by difficulty group

Ever been to school?	*yes*		*no*
	freq	*(%)*	*freq*
moving difficulties - polio	42	*(75)*	14
moving difficulties -other	20	*(65)*	11
learning difficulty	7	*(64)*	4
epilepsy	4	*(67)*	2
speech and hearing difficulties	11	*(69)*	5
multiple difficulties	21	*(45)*	26
seeing difficulties	2	*(29)*	5
Totals	***107***	***(61)***	***67***

Respondents were asked what kind of primary school they had attended. Of the 107 who had been to school, 11 (10%) had been to special schools. 97 (90%) had been to mainstream school. Again, there was variation according to difficulty group. The relative coverage of mainstream schools, and special schools by difficulty group is indicated by the following table:

Table 8: coverage of mainstream and special education in Bangalore Community Study

	never been to school	***mainstream school***	***special school***
moving difficulty - polio	13	42	1
moving difficulty -other	11	18	2
learning difficulty	4	7	0
epilepsy	2	4	0
speech and hearing difficulty	5	7	4
multiple difficulties	26	18	3
seeing difficulty	5	1	1
total	***66***	***97***	***11***

Thus, the coverage of mainstream schools is nearly nine times greater than special school, and the number never going to school is six times the number going to special schools.

answer: 62% of persons with disabilities over the age of 5 years had been to school. It appears that persons with disabilities are less likely to go to school than the urban population in general. Nearly nine times as many persons with disabilities have attended mainstream schools than attended special schools.

Question 2.3.2: what are the barriers to mainstream education?

⊗ **physical access as a barrier to school**: Physical access is a barrier when schools are too far away for someone with a moving difficulty to get too, and when access to school buildings is blocked by steps:

> "I studied till 7th standard but had to stop as there is no high school in this area. So I could not study further as I cannot travel. My parents used to carry me to and fro to school. But for 3 years I have been moving about on a wooden trolley made by my

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

> uncle, but the school is too far for me to go like that. I am interested in learning a trade where only hands are required wants to work". *man, 16, with polio. 056*

> "In a normal school, a government school, they refused to take my child in the higher class as it was upstairs because she couldn't climb, and so had to be in a lower class which was downstairs. The government is the worst culprit, they are not helping the disabled". *mother of girl, 11, with a moving and learning difficulty.*

> "We cannot walk easily to school... but we get there. It is difficult for us to get up and down from the bus and hard to climb up and down the stairs at school and we have difficulty using the school toilet. We cannot carry big weights, so if someone will bring our school bag and tiffin to school it is easier".
> *girls with moving difficulties between the age of 10 and 15, Kamalnagar FGD*

⊗ **lack of school going culture as a barrier to education**: In some of the low income communities sampled, none of the children in households were attending school, so it was not surprising that children with disabilities were not attending:

> "She can understand what everyone says. She does not do any work at home or anywhere else. She spends time sitting in one place and talks to a few friends, eat and sleeps... no, we are not thinking of sending her to school....in fact, her elder sisters and brothers are not educated either".
> *woman, 19, with Moving and learning difficulties. 076*

> "...my son is irregular at school. He would rather just play with the other children".
> *mother of boy, 7, with moving difficulty. FGD4.4*

⊗ **children in mainstream school but without appropriate support; negative experiences at school; exclusion from school because of difficulties; unacceptable behaviour:** These four barriers are often interrelated. Parents of children with learning difficulties reported that they had been to school but commented that "they were simply sitting", usually at the back of the class and with no additional attention or appropriate inputs from the teacher. Some stayed in the same standard for several years, others were promoted according to their completion of years rather than their academic ability. Such children might stay in school until they encountered an unsympathetic teacher who would not keep them in class; were asked not to come if their behaviour became unacceptable; or were withdrawn when it became clear to parents that they would not pass exams.

> "He can't do anything by himself. He repeats whatever we do. He is dull. His younger brother and sisters are studying well; but he is not - he has learnt to write his name only. Though he can't study properly, teacher is keeping him in the class. He does whatever we say and is slow in everything. He couldn't bathe himself until he was nine. He was not able to wash himself after toiletting. I used to beat him and taught him. Sometimes even now he can't wash properly". *mother of boy, 14, with learning difficulty. 004*

> "His only problem is that academically he is unable to learn anything - numbers, alphabets, colours etc. The teacher confirms this. He has changed school twice but still he can't learn. Since he was 3 years old he has been going to school. He talks to others and is aware of what is going on but academically is just unable to learn basics"".
> *mother of boy, 6, with learning difficulty. 046*

Children with speech and hearing difficulties had similar problems. They attended school, but were unable to learn using the teaching methods available:

> "The other boy died at home. NIMHANS said that we would have to come regularly for treatment, but we couldn't afford to go - someone had to take him, and the journey was too difficult - he is a big boy".
>
> *mother of man, 23, with severe moving, communication, and learning difficulties. 013*

> "He started getting fits 7 years ago and was getting treatment at NIMHANS. He stopped taking the medicines because NIMHANS is too far away for us to go and collect them. He gets fits once in 4 or 6 months... Sometimes he gets fits and falls down and there is no-one there to help him as we are at work and his brother is at school. Only for fits have we taken him to NIMHANS - for his hearing problem we have not showed him anywhere".
>
> *mother of man, 22, with learning, moving, hearing difficulties and epilepsy. 029*

Another dimension of time as a barrier is waiting time. This was particularly reported in association with NIMHANS:

> "For the past one year we have stopped taking her to any place. We once showed her to NIMHANS and they prescribed drugs for her fits. We stopped going to NIMHANS because we had to wait a long time - for a whole day - and so we started showing her to private nursing homes. Then the other children were born and we had financial difficulties, so we stopped taking her to any hospital".
>
> *mother of girl, 8, with learning difficulty and epilepsy. 028*

Some parents found transport-related barriers insurmountable after a single visit. The inability to make frequent service visits is also discussed below in the experience of those with multiple impairments. In summary, the time, effort, and costs associated with repeated visits to a service centre are an additional barrier because of which medical services do not meet the needs of persons with disabilities.

Time was also a barrier to the few services described which passed on skills for physical management exercises in the home. Shortage of time combined with a lack of understanding of why the exercises were to be performed, and dissatisfaction, or boredom, with exercises which did not lead to any obvious improvement.

A final barrier was an apparent lack of confidence and motivation to use medical rehabilitation services. Apparently small problems became insurmountable barriers, particularly for poor people:

> "She can neither hear nor speak. Her milestones were all delayed. We took her to K.C. General Hospital. These they said she would get her speech and hearing as she grew up. When nothing happened she was taken to NIMHANS when she was about 10 years old. She was treated there and told to come again after a few days. We lost the receipt which had her file number, so we did not go again. We did not try any other treatment.
>
> *mother of woman, 23, with learning, speech and hearing difficulty. 009*

☹ **physical access:**

> "...sometimes I feel dizzy, my head aches and I feel weak. When I used to take medicines I was better. They took me for this to NIMHANS and was given two injections every month and tablets everyday. [*There were no fits*]. For the last 4 months I have not been taking the medicines as we have to go to NIMHANS for this and it is very far away. I cannot walk, cannot climb the bus steps, and cannot climb the steps at NIMHANS. An auto would be too expensive".
>
> *woman, 60, with moving difficulty and strange behaviour. 116*

☹ **perceived quality and effectiveness of service delivery:** Some services were rejected because of the poor treatment by service providers:

> "We took him to Victoria where they did plaster of Paris but he did not improve, and they were careless in looking after him so we stopped the treatment, they had said that he was to be operated but we didn't want it. Till 7 years he was not walking and slowly after this he learnt to walk... he also had to be fed before. We went to a faith healer and we were given some powder to apply. He improved after this".
>
> *father of boy, 14, with moving difficulty.* 119

> "I was also treated at Puttur with massage and exercise for 6 weeks, but did not improve. Then we were fed up and my parents gave up taking me anywhere else".
>
> *man, 19, with moving difficulty following spinal injury.* 033

☹ **direct costs of service use:** The costs of surgical intervention are a particularly large barrier to service use for some most families of persons with disabilities. Even if an operation in a public hospital is free, the costs of admittal and lying are considerable. Where public services are not available, use of private medical facilities exacerbate costs. The 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:

> "He was born with his feet turned inwards because I was exposed to an eclipse during pregnancy. I took him to Victoria hospital where they would not operate on him as they said it was too soon. Then we took him to Maruthi nursing home, and they operated. We spent about Rs.900 on this. And he then wore callipers. He can now walk but still his feet are not straight. We went back to Maruthi, where they said that he would have to have another operation. Because the operation is expensive we are delaying this".
>
> *mother of boy, 8, with moving difficulty.* 030

> "He was born with a cleft lip and was taken to a private doctor, he was very small and weak and was treated for a long time to become strong and healthy. The doctor told him that he could be operated on, but we had no money. Then seven years ago he had a stomach infection and had an operation for this at Ramaih Hospital. For this I spent Rs.80,000 as he was admitted for 4 months. After this there was no money for the cleft lip operation. Now we have lost interest in getting the operation done - even in a Government hospital we would have to pay everyone from top to bottom as everybody is corrupt".
>
> *father of man, 22, with cleft lip.* 197

When anticipated costs were too great, some families found their own low cost solutions:

> "....we took him to Victoria, Martha's, Phelomena's, NIMHANS... everybody said it was polio. After different kinds of treatment he was able to sit up. But he can't use his legs. He was advised to have operations, but we didn't have the money, so he goes about on his wooden trolley which his uncle made - he's been doing this for three years".
>
> *mother of boy, 16, with moving difficulty.* 056

The direct costs of medical services were also a barrier to managing epilepsy. Some managed to meet these costs:

> "He used to get the fits twice or thrice in a week. Now after his treatment from NIMHANS he stopped getting that often. He gets once in a month, that why even after completing the treatment for five years the doctors at NIMHANS told him to continue treatment for two more years. I have to pay Rs. 150 per month for his medicine and I have to take him to NIMHANS for check up once in three months. I leave home by 8.30.a.m. and get back home around 4.30. p.m. Usually my wife takes him, but I also take him at times".
>
> *father of man, 17, with learning difficulty and epilepsy*

Others could not afford to buy medicines, which could have serious consequences on their quality of life:

> "I left my family in Tamil Nadu because of my fits and came to stay with my brother. He feeds me and I spend the time roaming the slums. I have fits, and sometimes I don't know what I am doing and where I am going. When I have fits outside people see me and fetch one of my kin to help.. they put a piece of metal in my hand. At Pondicherry I was given gardinal tablets, but I don't remember the course of treatment. I tried to get the tablets here in Bangalore, but it is not available. I had a prescription but lost it and cannot get the tablets without a prescription and moreover I don't have the money to buy them. I have fits about once in 2 weeks". *man, 45, with epilepsy. 129*

answer: barriers to medical rehabilitation include:

1. **environmental:** distance to centre-based services and difficult physical access to hospitals
2. **economic:** direct costs such as fees; and transport, time, and indirect costs related to distance, particularly of frequent service use.
3. **structural:** delivery in a single institution makes distance related costs inevitable.
4. **attitudinal:** perceived poor quality and effectiveness of service delivery

Question 2.4.4: is the use of medical rehabilitation services sustained?

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, or because the barriers to service use became insurmountable.

answer: use of medical rehabilitation services is not sustained.

Question 2.4.5: what are the specific needs of persons with severe and multiple impairments?

Those with severe and multiple impairments have more fundamental needs to address before inclusion in education and employment are prioritised. Families generally expressed that persons with severe and multiple impairments would never be able to go to school, and never be able to earn their living. This was not universal; some mothers hoped that their children would "get better", go to school, get a job, and marry. However, most of the families of older persons with multiple disabilities had more limited expectations, and focused on needs within the home. The expressed needs were for i) self management skills; ii) related need for income; iii) appropriate information and emotional support; iv) needs relating to behavioural difficulties.

i) Need for self management skills: Many difficulties described, and needs expressed, relate to absence of skills self management. Section 2.3 described that the parents of many of the children with moving difficulties want their children to do well at school. Parents of those with learning difficulties and severe and multiple impairments described more fundamental learning needs, such as more independent toiletting, washing, eating, and basic education skills, to enable the person with disability to increase their ability to manage their own life. A few family members described that learning these would improve their loved one's quality of life at the home. However, more usually expressed was a desire that something could be done to reduce the person with disability's dependence on the time and effort of other family members. Mothers usually did most in supporting persons with disabilities.

> "She attained puberty at 16 years and could not understand what was happening. She could not clean herself, could not put her clothes on, could not bathe herself, and cannot eat herself". *mother of woman, 22, with moving and learning difficulty. FGD2.3*

However, few mothers were aware that anything could be done in such situations. An exception is this example:

> "The whole day he sits in the lane and when it rains he gets inside the house, otherwise he only comes inside the house to have food when his brothers are not there at home. He sleeps outside. I cannot give him bath and change his clothes because he doesn't co-operate, some times he twists my hands even while washing him after defecation, I need his brothers support to wash him. It is all right if he sits in the lane the whole day as someone will give him food. But I would be grateful if some one can help him stop defecating in the night in the bed."
>
> *mother of boy, 15, with learning difficulty. In depth*

Other mothers commented on the socio-economic aspect of this dependence on their time. If they always had to be on hand to look after the person with disability, they were unable to go out and earn money:

> "Can my son's brain develop so that he will be able to do some work?. Although I was a class 11 student, I have not worked as I have to be here for him all of the time. I have to tie him to a table when I do the household work. We don't take him anywhere even for family functions as he is difficult to carry. He has no toilet control. He cannot hear properly either. He cannot recognise outsiders, only family members... this is because he spends the whole day at home with me".
>
> *mother of boy, 11, with moving and learning difficulty.* 102

> "Although we are in financial difficulty, I cannot go out to work as there would be no-one to look after her... she behaves strangely, she spits in peoples' faces, shits and pees in public places. She cannot dress herself".
>
> *mother of girl, 13, with learning difficulty and strange behaviour.* 005

> "How can I leave her and go to work? Who will attend to her when she shits and pees?"
>
> *mother of girl, 9, moving and speaking difficulty.* 125

For others, the need to earn money took precedence:

> "Both her parents have to go to work - her father is a painter, mother is a housemaid. Her sister goes to school. Her mother leaves early but comes back at 2.30. Her 6 year old sister buys her breakfast, and she gets her lunch from FIDES - a local NGO. We neighbours help her to get about sometimes. When she was 1 year old, the corporation gave an injection... I don't know what it was for, she got a big swelling in the spot where the injection was given on her right buttock and it was infected... it was treated by a private doctor and only then did she become like this... she spends the whole day sitting outside the house, she has no urine or toilet control, if she passes stools or urine no-one takes care of her until her parents or sister come back from work. She cannot eat herself".
>
> *neighbour reporting on girl, 4, with speaking and moving difficulty.* 099

In light of such socio-economic difficulties, and the impact of providing constant care without any break, some family members inquired about residential care. However, it is important to note that none of the persons with disabilities expressed the need to be placed in residential care. Most of those with multiple impairments were not in a position to comment on the need for hostels. However, a mother of a boy with polio commented:

> "We are planning to put him in a hostel in Tamil Nadu where they are giving schooling and vocational training. But he doesn't want to leave us and go".
>
> *mother of boy, 4, with moving difficulties from polio.* 136

Others had been advised to place their child in a hostel but had themselves rejected this:

> "We took her to NIMHANS and she was diagnosed but they did not tell us the diagnosis. They said to put her in a hostel but we don't want her to be in a hostel".
>
> *father of girl, 12, with moving and speaking difficulty.* 141

Families' desire to find a hostel in which to place the person with disability was also related to poverty as it was perceived that hostels could provide food and care free of cost. Other people were against their family member being placed in an institution as they would look after them for as long as they could. However, worries about what would happen after this carer's death were expressed by many. This concern for future circumstances again reflects the changing needs of persons with disabilities across the age span:

> "As long as we are there we can look after him, but after we are gone what will happen to him? He has two sisters but after they are married what is the guarantee that their husbands will take care of him?"
>
> *mother of boy, 11, with moving and learning difficulty.* *102*

This fear for the future was compounded by the fact that many people, especially mothers, are the supporter of those with severe and multiple impairments. Mothers approaching old age with dependent adults could not rely on the support of other family members now, and perhaps less so when they died.

ii) Income: As already described, one result of the need for constant care was that the carer could not go out and work. Some parents of persons with multiple disabilities expressed direct need for income to support the person with disability and the rest of their family. In discussion, carers asked the fieldworker if they would get any money in return for discussing their experiences. 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. Other mothers had considered starting a small home based business so that they could be available to support their disabled family member but 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 the money from money lenders. They had heard that government bank loans were available, but again did not know how to apply for this.

iii) Needs for practical information and emotional support: Through talking to the families, a need for 'counselling' was clear. The term 'counselling' could be interpreted formally or informally. Parents of people with severe and multiple impairments had sought advice from medical rehabilitation services, but rarely had their need for information been sated. Some were left confused and frustrated, having neither information about their child's impairment, or about current and future expectations for rehabilitation inputs and abilities. Again, some medical practitioners had given conflicting advice, and confused people by their actions. In the short term people were likely to seek alternative medical opinion. In the long term many abandon their attempts to seek rehabilitation inputs, medical or otherwise. There is very little evidence to suggest that medical practitioners give practical advice to poor people.

Many persons with multiple disabilities and mothers spent their entire time in each others company, with little external interaction. It was unsurprising that both appear to need additional sympathetic social interaction. Some of the mothers interviewed had not spoken about their feelings and concerns for a long time.

> "Her mind is not right. She is 32 but can only say *amma* and *thatha*. She doesn't allow anyone to touch her, she is afraid of strangers. She just doesn't want to come out of the kitchen. She wouldn't even allow me to touch her. It is better for us for her to die. She puts on clothes if given to her, but cannot put them on properly. She can wash and bathe, she crawls cross legged and uses a commode but she doesn't know how to sit on it. As long as I am there I can look after her, but who will look after her after me, I have had enough of her... let her die. She doesn't want to come to any doctor. She refuses to swallow tablets. She has regular monthly periods but doesn't know how to take care of herself. She doesn't tell me when they come. What to do with a child like this? God has given a child like this. When she was in the womb, my husband killed a monkey and maybe because of that curse she was born like this". *mother of woman, 32, with*

> *speaking, moving and walking hearing difficulty and epilepsy.* 127

Even those with other family members did not necessarily get emotional support, and the presence of a person with disability might cause additional family problems.

> "At home his brothers and sisters tell me to 'serve his food outside the house, because he stinks'. They feel awkward eating with him inside the house. When his brothers are at home I serve him outside, when they are not at home I serve him inside. He sleeps alone outside, I make his bed outside because he passes stools in the bed and his brothers don't like it. They say 'when we get married what would our wives feel about us with him like this, who will give their girls to us for marriage?".
>
> *mother of boy, 15, with learning difficulty.*

There was also an obvious need for emotional support and counselling for some persons with disabilities who felt that they were a burden on their family:

> "I am very frightened to think about the future. It is very difficult for boys like him. If a child is severely disabled and is MR, the child does not realise what he is missing. But my son, being intelligent, feels acutely his lack of ability to do things. He is embarrassed that I have to take him to the toilet. But there is no choice. He has shown no awareness about sex and I have not talked to him on the topic. I just can't".
>
> *mother of man, 20, with severe moving difficulty.*

iv) Needs relating to behavioural problems: Other families described important problems resulting from their children's unacceptable behaviour. A need for advice was also expressed by the families of adults who had been identified as being "mentally retarded" but were almost certainly mentally ill. Two major problems were described. Firstly, violent behaviour, in which someone else might be assaulted but equally resulted in person with disabilities being beaten by others. Secondly, the safety of young girls and to a lesser extent boys who roam about the community, in some cases not wearing their clothes.

> "When 8 years old he was going to school and father was working at HMT and he was fine. One day coming back from school a scooter hit him and he was admitted into HMT hospital - he was treated for superficial bruises and discharged. Slowly his behaviour began to change and used to run away, started abusing everyone, biting people, and used to fall unconscious when beaten.... Even before the accident he was not speaking much and people said that his brain was weak. We took him to NIMHANS and he was admitted for 8 long years.... he used to be tied to his bed and have injections administered.. 4 daily, plus tablets. After this they said nothing more can be done. His skull was injured and if it heals he will be OK. We also took him to KC General and he was treated for 6 months - with the same tablets and injections - but they did not help. We tried native medicine like serpents' skin powder applied to his scalp in our native place, and visited many temples but nothing helped. We used to go once a month to NIMHANS to take medicines but for the last 10 years we have not been going as it was difficult to take him - I cannot leave him alone and have to do everything for him. My life revolves around him. He is chained by his feet so that he cannot run away, if he goes far he gets abused and he gets a beating, so for his own protection I chain him up. He was not up to the capacity of a normal boy his age. If left by himself he walks far off, where will I go searching for him? My other sons have deserted me and I have now left everything to god's will". *mother of man, 27, with strange behaviour.* 166
>
> <u>fieldworker</u>: *"he was smoking a beedi outside the house. When I spoke to him he turned away. The nearby shop keeper gives him beedi whenever he asks for them. The shop keeper says that he does this to keep him happy - otherwise he abuses him and becomes violent".*

the police. NIMHANS made us pay Rs.300 for consultation. Even to just bring him back home we had to pay the Rs.300".

mother of boy, 9, and girl 12, with moving and learning difficulties

Needs for inputs for modification of unacceptable behaviour were unaddressed. With regard to socio-economic support, none of the people with severe or multiple impairments, or their families had received loans. Only eight of the 54 with multiple difficulties, and one of 13 with learning difficulties, had received a pension.

answer: The needs of persons with severe and multiple impairments are not met by medical services.

Question 2.4.7: what are persons with severe and multiple disabilities' experiences of medical rehabilitation?

Common themes in medical rehabilitation 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":

> "The diagnosis was done at NIMHANS and they said that nothing could be done.. they said to go to the rehabilitation centre for the Mentally Handicapped but my husband felt there are only trainees there trying to learn - they wouldn't be able to do anything, so we brought him back home, and since then he doesn't go anywhere. We took him to St Johns [Medical College] and they said nothing can be done..." *mother of man, 19, with learning difficulty. 103*

- Parents pursue cure from several places.
- Different doctors prescribe 'medicines' (largely tonics and vitamins), with no improvement.
- Mother continues service seeking, and is advised to bring her child regularly to centre-based service for exercises to be performed, which she initially tries to do.
- Mother finds travelling to centre based service too difficult as son 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 develop into needs for self management skills, but from past experience 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 this child and the whole family to have a secure future together.

Despite pursuit of medical rehabilitation, most real needs are not been addressed. Most of the families of persons with multiple difficulties had undergone some of these experiences as their child got older. 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 less of a concern. They were looked after as if babies and at such a stage, many respondents reported that they had managed their child's needs relatively easily. Difficulties developed when the person was still dependent on a family member later in life.

answer: as age increases needs develop, yet service use decreases because needs are not met and associated disillusionment, and because of barriers associated with the centre-based organisation of services.

Most families were unable to do anything about such behaviour other than keep the person with disability under constant supervision, or if this was not possible, keep the person locked in the house, or tied up with rope.

> "He has the habit of roaming the slum and collecting and folding paper. People tease him and he scolds them back, beats them and throws stones. Once he smashed the window of a bakery. When we hear people teasing him we fetch him home".
> *brother of man, 23, with learning difficulties, and epilepsy.* 151

None of those interviewed reported having had any practical advice about methods for helping the person behave more acceptably.

answer: in general, the needs of persons with severe and multiple impairments and their families are for:

- **self management skills**
- **income**
- **residential care**
- **counselling; practical information and emotional support**
- **management of behavioural difficulties**

Question 2.4.6: are these needs met by available services?

The community study found that pursuit of rehabilitation by parents of those with severe and multiple disabilities is typically medically oriented and involves considerable effort and cost, but rarely meets real needs, particularly as age increases. This disparity between need and service delivery is most apparent with regard to needs for self management skills. Very few respondents had received inputs for these, despite using medical services. This was partly because they had started and finished service seeking before their child was of an age when independent toiletting became important. When advice was given it was inadequate and not delivered sympathetically:

> "I took him to NIMHANS thinking that they would give him some tablets for a cure, but they threw a pin in front of him and asked him to pick it, he ran and picked it up and put it in their hands, and they told me 'you are the mad one: he is fine'. They just told me to take him to toilet and show him how to use it. I tried teaching him but he never co-operated and I gave up". *mother of boy, 15, with learning difficulty.*

Medical rehabilitation focused on diagnosis, mobility (where appropriate), and prevention of further deformities as for those with moving difficulties described in section 2.4.1 above. Positioning for improved function was described by some, but this was limited to sitting and not associated with activities.

Counselling, in the form of appropriate, practical information and emotional support, was not available from medical rehabilitation services.

> "When my daughter was one year old she had polio drops and from then on started getting fits. She couldn't walked properly or talk properly. We showed her at a government hospital, where they gave an injection and sent us home. There was nothing else, and nothing was told to us. My son was born three years later. When he was one month old he got fits. We never showed him to a doctor. We were poor, we had no means of getting medical aid. After that we came back to Bangalore.... Two years back we went to NIMHANS.... I don't know what the doctor said to us. We never went back. Anyway, we only went there because my son had wandered off and not come home. After two weeks we found him in NIMHANS. He had been sent there by

(reviewed in section 2.3) is small. 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. Others had not got aids because of their cost.

> "We took him to Malleswaram, but they said that to make calliper would cost us Rs.4000 so we brought him back, we cannot afford that. No-one in Karnataka makes free callipers... only in Tamil Nadu do they make them free".
> *mother of boy, 4, with moving difficulties from polio.* 136

Cost is also a barrier to the use of hearing aids.

> "They both have hearing aids, which cost Rs.5000 each, but now they are both out of order and so not being used". *mother of two boys, 13, with hearing difficulty.* 145

Overall, the effectiveness of the provision of aids and appliances in addressing needs for improvement of functional abilities is in doubt. Aids and appliances constitute a major part of the medical rehabilitation services in Bangalore, and yet it appears that many of the aids supplied have little functional impact.

answer: medical rehabilitation was less prioritised than needs for income and education. Qualitative data indicates that experiences of medical rehabilitation are characterised by a failure to meet needs for appropriate information, or for improved functional ability.

Question 2.4.3: what are barriers to medical rehabilitation services?

Over 85% of person with disabilities had made contact with medical rehabilitation services during their life. In many of the experiences described, medical rehabilitation services did not meet needs. Beyond this, the community study found that medical rehabilitation services, all centre-based, are characterised by barriers to their use, particularly by those from low income communities.

⊗ **time and the indirect costs of frequent service use:** Centre based services are inevitably a considerable distance away from most communities, thus visits require inputs of time, and money for transport costs.

> "The hospitals are too far". *mother of woman, 18, with epilepsy.* FGD4.7

children with disabilities with moving difficulties had generally been advised to attend hospitals regularly for physical management exercises, but found repeated visits difficult to make. People perceived one-off service use for curative purposes as possible, but such regular service attendance was not. Hospital service hours are during the working day; most parents had work or household duties during this time. Repeated time off was not possible; the self employed could not earn enough to allow this, and few employers would permit it on a regular basis. Interrupting household work effected the rest of the family as mothers had to leave the house early in the morning in order to attend hospitals on time, and so could not cook for their other children. Without food, these children could not go to school. The cost and practical difficulties associated with public transport were also a significant barrier. Thus, for many, their first service use was also there last, regardless of the advice given. For example, one respondent had been severely injured when climbing an electricity pole. His friend had died in the same accident. He was admitted to hospital for two weeks and then referred to NIMHANS:

Question 2.4.8: what are barriers to rehabilitation services for persons with severe and multiple impairments?

All services described by respondents are based in single centre institutions. Many of the barriers described by the parents of those with multiple impairments were the same as those described for all persons with disabilities:

- ☹ **distance from home to centre**
- ☹ **transport effort with child**
- ☹ **transport time**
- ☹ **transport cost**

☹ **costs of medical rehabilitation:** Descriptions of the costs of medical rehabilitation were similar, but more extreme, to those of persons with moving difficulties described above. Costs multiplied for those who were advised to have neurological tests.

answer: the barriers to medical rehabilitation are the same as for other persons with disabilities, mostly related to the centre-based orientation of medical services. For this group, barriers are increased by advice for regular attendance and difficulties related to transport, particularly as persons with disabilities get older. Most relate to the centre-based nature of medical services.

Question 2.4.9: what are persons with disabilities experiences of residential care?

The persons with disabilities interviewed in the community study were all found at home. Therefore, persons with disabilities who were in residential hostels were unlikely to be sampled and few of those interviewed had experienced institutional care. One family with a son with multiple impairments and one with speech and hearing difficulties had tried the hostel option but with poor outcomes:

> "As he grew up he used to wander about and would not come back home so when he was about 15 he was put in a remand home hostel near Madiwala Check Post. He was in the hostel for 3 years and was ill treated - he was beaten on the head for not co-operating, and would not eat, and wandered around. So we brought him back home. His behaviour had become worse and now he gets fits about once a month although he is regularly on Gardinal tablets. I go to NIMHANS once a month and get the tablets, but he doesn't go for check-ups. The last check up that he had was about 10 years ago.
>
> *father of man, 27, learning difficulty and epilepsy.* 105

> "One year back we sent him to a hostel for children with speech difficulty where schooling was also available... near Yeshwantpur, but he stayed for a month and then came home...he did not want to go back. He does not tolerate anybody outside the family hitting him, such as teachers and classmates, and so refuses to go to a hostel school". *mother of boy, 9, with speech and hearing difficulty.* 181

However, the general experience was that hostels were not available to persons with disabilities, particularly from low income households:

> "I also heard through a friend about Association of the Mentally Handicapped, where this friend's son is staying in the hostel. I want to put my son also there, but I heard through my friend without the influence of some eminent people it is difficult to get a seat there".
>
> *mother of man, 17, with learning difficulty and epilepsy.*

answer: only two of the 200 persons with disabilities had any experience of residential care. Both had left because of negative experiences.

2.5 Integration of services

Question: is there evidence of integration of the varied rehabilitation services used by persons with disabilities?

There is evidence of referral within the network of government medical services. The Bangalore community study found that the only integration between service sectors is the link defined by medical assessment for medical certificates as a prerequisite for welfare application, but this affected a small number of people as coverage of government welfare provision was limited. For the majority of persons with disabilities, there is no integration between services.

2.6 AGE ISSUES

Question: are there age dependent trends in needs and experience of services?

Only one person with disability over the age of 55 was interviewed. Older people were not identified by the key informants. Therefore conclusions about the needs and experiences of people who are both disabled and of advanced age cannot be made. However, reviewing the coverage of the services described by persons with disabilities indicates that there are few, if any, virtually services for old people.

The study does, however, illuminate considerable age-dependent trends in needs, service use, and service provision. Of all service provision, medical rehabilitation services are the most frequently used. 85% of respondents had used a medical rehabilitation service at some time. This typically takes place during the first few years of childhood, when parents seek curative services and information. Some end their service use at this time. Others persist with medical rehabilitation. Generally, with age, needs evolve away from medical and towards education and work. Regardless of the appropriateness of medical rehabilitation services for meeting medical needs, there is far less provision of rehabilitation services to support education and work. Thus, persons with disabilities who are excluded from mainstream schools, and cannot secure mainstream work have no support after their early contact with medical services.

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

2.7 GENDER ISSUES

Question: what are the gender-specific experiences of persons with disabilities?

There was no relation between gender and the types of difficulty represented in the sample. Gender specific experiences of persons with disabilities largely reflect the gender specific experiences of the population at large. The quantitative data did not indicate any significant differences in the experiences of service use by male and female persons with disabilities.

66% of men and 58% of women had attended school but this difference was not statistically significant. The average school attendance for the 5 to 15 age group can be estimated for urban Kamaraka for the year 1987-88 as 74% and 71% for boys and girls respectively[8], thus it appears that persons with disabilities experience the same gender bias in access to school as the population at large. In the community study sample, 25% of people over 15 years old were doing paid work, and women with disabilities were as likely to be doing paid work as men. Many women also do household work, they are even more economically reliant on other people, and have less control over their own lives. 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

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[8] National Sample Survey Organisation, Government of India (1992). In *Report of the education commission, Government of West Bengal.* August 1992.

girls than men and boys. The added risks of assault and abuse were raised particularly for those with learning difficulties.

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answer: although some respondents thought that access to school and work was less for women with disabilities, the data collected did not indicate a significant relationship. Concern for the safety of persons with disabilities was gender related.

2.8 COMMUNITY LIFE

Question: how are persons with disabilities treated by their own families and by the community?

Persons with disabilities who were participating in mainstream life, such as attending school or working were reportedly treated as any other person. Those with greater difficulties, and less immersed in the life of the community, were more likely to be treated negatively by other people, including their own family members. Some extended families treated them with love, respect, and shares responsibility for their support. In other families, care for a person with disability was the sole responsibility of one member, typically the persons' mother. An important bridge between family and community life is attendance at social functions such as marriage parties. This subject was raised spontaneously by some persons with disabilities, as well as pursued in qualitative questioning. Most persons with moving difficulties resulting from polio attend all social functions with their families. Others with moving difficulties might be excluded because they had mobility difficulties:

> "We don't take him anywhere even for family functions as he is difficult to carry".
> *mother of boy, 11, with moving and learning difficulty.* 102

Many older persons with disabilities were excluded from such functions by family decision. For some this was because they would have to be carried. For others, the reasons were less palatable. Typically, people with learning difficulties who do not have toilet skills, children with multiple difficulties, and people with strange behaviour are excluded from social gatherings:

> "How can I take him [*to social functions*], he doesn't want to wear clothes, and he doesn't want to sit in autos". *mother of boy, 15, with learning difficulty*

As with family attitudes, respondents described a continuum of experiences in the community, from descriptions of special efforts made by neighbours to help them; to those who are treated like any other citizen; to persons with disabilities exposed to extreme verbal and physical abuse. In general, those with moving difficulties were treated better than those with learning difficulties and multiple impairments.

> "People are helpful - they draw water for us". *girl with moving difficulty. FGD3.1*

> "She stays in the neighbour's house from morning to night as we are all at work. They take care of her". *sister of girl, 12, with learning difficulty and epilepsy. FGD4.7*

Negative attitudes present themselves by degree. Some persons with disabilities were physically attacked. More were subject to name calling, or questioned about their impairment. Unprompted suggestions about the cause of a person's impairment were common. These were also aimed at persons with disabilities' mothers:

> "My neighbours are saying '*What karma have you done? What sin have you done such that you have to touch shit with your hands'*. They say this because I have to clean him up after defecation. Some people say what a pity that he is born like this. Otherwise nobody says anything. Occasionally on festivals days some one may give him some food, other than this he doesn't get any support from anybody in the community".
> *mother of boy, 15, with learning difficulty*

> "Once we went to a temple about 2 years back and the priest saw my boy and said *"this boy must have cut off someone's legs in his previous birth, that is why god has punished him like this"*. This had a deep effect on Anant and he began to believe that this was true. He went into laughing convulsions, moody fits and indicated 2 or 3 times that he wanted to commit suicide - he would put his finger in the electric plug, and move his eyes heavenward. He had to be taken to NIMHANS and be treated, for almost a year his restlessness continued. Now he is much better and everyone advises him that it is not his fault". *mother of man, 20, with severe moving difficulty*

It was commonly reported by children with disabilities and their families 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.

> "I want to play cricket with the other children, but I can't as I fall... but my social life is not affected very much... only when I beat my friends they call me lame and then run away".
> *boy, 13, with moving difficulty. 002*

In a handful of cases, community organisations, such as youth clubs, and political parties had acted with one-off, material efforts, as had Lions and Rotary clubs further afield.

answer: experiences of community life vary. Many positive examples and many negative experiences were discussed, but virtually all persons with disabilities received support from their families.

Question 2.8.1: 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; others were not expected to get married. In one FGD with women with moving difficulties in Koramangala over half of the 10 women were married to their maternal uncle. This is not uncommon in the community at large. It is a welcome option for older men who have failed to find a match. Some families favour it as in theory it will involve a smaller dowry. These women reported that their parents felt that a family member they would look after them better, but also said that their husbands loved them. They said that their husbands "keep them happy, take them out. The do not comment about our disability".

answer: some persons with disabilities do get married.

Question 2.8.2: what barriers are there to persons with disabilities getting married?

Several of the key issues in determining whether marriage is possible for persons with disabilities are described in the following account:

> "Doctors said that there is no cure for him. As long as we are there we will take care of him. All that he needs is he should have something for his living. I never thought of getting him married, but if another five to seven years go by and by then he becomes all right, we will see. Otherwise how would he feed his wife? He won't be able take care of his wife, only we would have to feed them. If he doesn't improve, it is better he remains single. Who will marry him he is like this. If he improved, some one may be willing to marry him". *mother of man, 17, with learning difficulty and epilepsy*

⊗ **the nature of an individual's difficulties**. Those with limited moving difficulties were regarded as the most suitable for marriage. Those with learning difficulties and multiple difficulties were the least likely to marry. Many parents of persons with severe and multiple impairments had never considered that their child would marry.

> "My husband buys the provisions and I cook. I cannot see at all but I can manage this without difficulty. So long as he fetches from the market I am fine".
>
> *woman, 29, seeing difficulty.* 100

> "We got married 9 months ago. My parents did not send me to school because I was getting fits. My husband is a flower seller in the market, and we stay with my parents in law. I get fits every full moon day and she have been to NIMHANS and been admitted, I had fits 6 or 7 times in three or four months. My condition did not improve - I took tablets for 3 years with no improvement, we used to get free medicine, but at the moment they have been refused the free medicine so get it from a private medical store. I get fits only at nights and moves about freely by myself. Though I am taking the tablets I still get fits... the fits have not affected my family or social life. My husband is understanding".
>
> *woman, 26, with epilepsy.* 122

Some women reported being deserted by their husbands because of their impairments:

> "I have polio. My daughter also has polio. I gave her sleeping tablets hoping that she would die. I thought - why should she suffer like me - my husband deserted me because my daughter also got polio - he married again and lives elsewhere, though he has now come back with his second wife and we all live together amicably... I have made up with my husband - he supports me and my family. I tried to commit suicide when my daughter got polio".
>
> *woman with moving difficulty.* FGD2.6

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

Question 2.8.4: is access to urban infrastructure difficult for persons with disabilities?

Persons with disabilities described the barriers which exclude them from water supply, sanitation provision, and public buildings, but did not express that their difficulties can be considered in future infrastructural development.

Question 2.8.5: what are the barriers to access?

Persons with disabilities described barriers to their use of facilities as varied as water supplies, roads, and public buildings. For example, pumps are too far or high, roads too rough with nowhere to cross, public buildings have steps. Some of these barriers are experienced by many urban residents who do not have impairments. The example of access to toilets is salient to illustrate the marginalisation of the needs 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 will contribute to the transmission of disease, to their households and communities. Section 2.4.5 described difficulties in safe toiletting for people who for various reasons do not have toiletting skills, and depend on family members to assist them in toiletting and washing afterwards. Others described barriers based on the difficulty in using the sanitation facilities available in their community. Another link between sanitation and impairment was the defecation in dangerous surroundings. More than one of the people interviewed had been involved in accidents while defecating; one had been hit by a train and been permanently impaired

☹ **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. Some of these were built by householders, others by municipal authorities. Other people live in communities where there are no Municipal sanitation facilities.

☹ **toilet unsanitary for non-walking users**:

> "There are toilets built by the corporation, none of them are in a good condition, it has either become useless due to maintenance or maintained badly. I can't get my tricycle up to them and I crawl, so I don't use them. An important difficulty for the disabled is to go to toilet because it is not clean, and the path to toilets are not clean".
>
> *man, 35, with moving difficulties from polio*

☹ **no water source close by**: An additional barrier to using community toilet facilities was that many toilets do not have water sources for washing close to them. Thus, those who could not move to the toilet and carry water with them were dependent on some to help them carry the water.

answer: access to sanitation and toilets is difficult as the needs of the whole community have not been incorporated in the planning of infrastructure. Thus, access and physical use may be difficult, not only for persons with disabilities but for others, such as old people and children, as well.

2.9. POVERTY ISSUES

Question: what is the relationship between disability and poverty?

Qualitative data from the more marginal communities indicated that provision of basic services, and health information are limited. In such conditions, incidence of diseases which may be associated with impairment is high.

Cost was named as a barrier to all rehabilitation services. Whether the barrier is a direct fee to a private doctor, a bus fare to a hospital, the wage lost while using a service, or an alleged bribe to a service provider, it is clear that cost is a greater barrier to poor people. This might make them use services less frequently, or stop them using services at all. When they did manage to pay costs, low income families reported that the costs of rehabilitation services further stretched their household resources.

Persons with disabilities appear less likely to do paid work than the urban population at large, and family members of some people with severe and multiple impairments report that they are unable to do paid work as they are supporting the person with disability. Extra costs incurred by family of persons with disabilities, and the reduced opportunities for family income generation would appear to further contribute to the poverty of already poor households.

answer: it is known that prevalence of impairments is greater in low income groups. This study found qualitative evidence that disability also causes increasing poverty.

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

Appendix 1: Types of key informant used in questionnaire study

Type of key informant	*freq*	*%*
local leader	64	32.0
met at/near house	71	35.5
local school staff	14	7.0
Community Health Worker	11	5.5
women's leader	3	1.5
shop keeper	2	1.0
other resident	5	2.5
service organisation	2	1.0
local NGO	1	0.5
missing	*16*	*8*

Appendix 2: Cluster communities sampled in questionnaire study

	Community	*number of interviews*	*%*
1	KS Gardens	1	.5
2	Sai Baba Nagar	3	1.5
3	Malleswaram	12	6.0
4	VST Colony	2	1.0
5	Wilson Gardens, Hosu	7	3.5
6	Drive-in Talkies	4	2.0
7	Basappa Garden	4	2.0
8	Bhavani Layout	1	.5
9	Hebbal	4	2.0
10	Mathikere	2	1.0
11	Haleguddadahalli	27	13.5
12	Anjanappa Garden	17	8.5
13	Yeshwantpur	3	1.5
14	Basawashwar Nagar	1	.5
15	Kamala Nagar	4	2.0
16	Sundaram Industries	3	1.5
17	Hal Main Road	2	1.0
18	Ulsoor	12	6.0
19	AK Colony (inc Yelan	11	5.5
20	Jalahalli	80	40.0
	total	***200***	***100***

Appendix 3: Descriptions of the 18 persons with disabilities interviewed who are working

	code	*age*	*m:f*	*difficulty group*	*work*	*how did you get this work?*
1.	15	38	f	moving difficulty - other	housemaid	99
2.	19	19	f	moving difficulty - polio	Tailor's assistant	through neighbour/friend
3.	58	19	f	moving difficulty - polio	rolling *agrabati* at home	learnt at home
4.	68	35	f	moving difficulty - polio	make *beedies*	learnt at home
5.	85	22	m	moving difficulty - other	washes intestines (butcher)	.
6.	92	14	m	moving difficulty - polio	rolling *agrabati* at home	learnt at home
7.	95	18	m	moving difficulty - other	construction worker	through neighbour/friend
8.	124	27	m	moving difficulty - other	in cycle shop	father got bank loan
9.	135	40	f	epilepsy	rag picker	doing since childhood
10.	137	18	f	speech and hearing difficulty	rolling agrabati at home	learnt at home
11.	138	33	f	moving difficulty - polio	factory store keeper	through relative
12.	144	45	f	moving difficulty - polio	housemaid	I went and found it
13.	154	42	m	speech and hearing difficulty	tailoring at home	doing since childhood
14.	176	18	m	multiple difficulties	workshop helper	through neighbour/friend
15.	179	16	m	speech and hearing difficulty	construction worker	through neighbour/friend
16.	192	41	f	moving difficulty -other	home tutor	learnt at home
17.	197	22	m	moving difficulty -other	sticks poster in theatre	.
18.	198	14	m	speech and hearing difficulty	workshop helper	through neighbour/friend

Appendix 4: Community study interview schedule

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?

CONTENTS

Section A - IDENTIFICATION
Section B - USE OF SERVICES
Section C - EDUCATION
Section D - TRAINING AND EMPLOYMENT

Section A -<u>**IDENTIFICATION SECTION**</u>

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*):

<table>
<tr><td></td><td>PRIMARY SCHOOL</td><td>SECONDARY SCHOOL</td></tr>
<tr><td><i>tick one only for</i></td><td>| | <i>special school</i></td><td>| | <i>special school</i></td></tr>
<tr><td>for primary and</td><td>| | <i>mainstream school</i></td><td>| | <i>mainstream school</i></td></tr>
<tr><td><i>one only for secondary</i></td><td>| |<i>other (what?)</i> ___________</td><td>| |<i>other (what?)</i> ___________</td></tr>
<tr><td><i>as appropriate</i></td><td>|<i>NA</i>|</td><td>|<i>NA</i>|</td></tr>
</table>

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 5: Guide for Focus Group Discussions (FGD) :

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)