

# The Handimachal Project

*("give a hand to the handicapped people of Himachal Pradesh")*

September 2007

## DISABILITY SURVEY REPORT AND PROPOSED PILOT PROJECT

in view of the creation  
of a medical, information and training centre  
dedicated to disability  
in the Kullu district of Himachal Pradesh

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# INTRODUCTION : MOTIVATION OF THE HANDIMACHAL PROJECT AND PRESENTATION OF PARTNERS

## Context

Himachal Pradesh has benefited from a certain amount of economic development during the last twenty years due to profitable activities such as tourism, hydroelectric projects, booming industrial projects and a flourishing agricultural sector. The level of schooling is in the process of being improved with the arrival of the new generation and high standard education. The influence of local tradition, together with an opening-up of scientific culture, have revealed a lack of comprehension in the treatment of certain sanitary and medical problems, in particular concerning physical and mental handicaps.

In spite of a growing increase in medical facilities in the urban areas of Himachal Pradesh (state and private hospitals, private clinics), the problems linked to different types of handicaps remain generally untreated (with the notable exception of a specialised institute for the blind and deaf in Kullu town) either by government institutions or by private organisations: therefore the affected families, without medical knowledge and no access to existing solutions, remain isolated.

## Definitions

Among the various (and sometimes complex) definitions and concepts found in the literature, we would like to retain those underlying the concept of "CAHD" (Community Approaches to Handicap in Development) defined by Handicap International, which best correlate with the Handimachal programme:

*Disability: "Disability summarises a great number of different functional limitations occurring in any population, in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature."*

*Handicap: "not recognizing the existence of disabled persons and people with impairments, their exclusion from society, and no provision of services to meet their needs."*

*Impairment: "Impairment is a loss or abnormality in body structure or physiological function (including mental functions)."*

*See Appendix 1 for full Key Terminology of CAHD as expressed by Handicap International*

## Project

During summer 2006, HPVHA Shimla was approached by a representative of the French NGO "La Maison des Himalayas" who resides part of the year in the Kullu district of Himachal Pradesh and who was personally confronted to the problems of disabled persons

in the district. HPVHA on its side had already been leading various awareness actions in the field of disabilities.

Both MdH and HPVHA agreed to join their efforts in implementing a tentative programme designed by MdH under the name of the "Handimachal project", i.e. mainly the creation of a medical, information and training center dedicated to disability in the Kullu district of Himachal Pradesh.

## **Partners**

### (1) "HPVHA" (Himachal Pradesh Voluntary Health Association):

Himachal Pradesh Voluntary Health Association (HPVHA) ([www.hpvha.org](http://www.hpvha.org)) is a state chapter of Voluntary Health Association of India, Delhi, and is a network of more than 60 NGO's engaged in health and development activities all over the State. HPVHA is working on the various issues and concerns of health since 1987. HPVHA is a registered non-profit-making society having a secular constitution which aims at improving the health of the people irrespective of the caste, creed, sex and religion. It assists in making health a reality for the people of Himachal Pradesh with their involvement and participation.

The organization works in the field of community health and helps the grass root level member voluntary organizations to plan, implement and evaluate their development programmes. Another important role that the organization performs is liaisoning for the grass root non-profit organizations with the State Govt., the Central Govt. and the International Agencies.

The organization is committed to promote Social Justice in the provision and distribution of health services in Himachal Pradesh. Presently HPVHA is involved in health related projects such as Women & Reproductive Health, Promotion of cultivation and conservation of the medicinal plants, Prevention and Control of STD / HIV /AIDS, Disability, Reproductive & child health, Training / Capacity building of NGOs Advocacy and Information Dissemination, Conducting Studies and Surveys, Research and Development.

Apart from all areas stated above HPVHA is engaged in various community intervention innovative projects including Tele Counseling and live counseling & HIV Testing centers on STD/HIV/AIDS Prevention & control. One targeted intervention on STD/HIV Prevention & control on Truckers. HPVHA is also working as Mother NGO for two district of HP (Mandi & Bilaspur) under Govt of India MNGO-RCH-II Programme.

HPVHA is member in various State levels Govt bodies e.g. State Population Commission, European Commission, State RCH Committee, State AIDS Control Society, State Mental Health Authority, State Blindness Society, State coordination committee on Population development programme.

### (2) "MdH" (La Maison des Himalayas, i.e. the House of the Himalayas):

The French NGO "La Maison des Himalayas" ([www.maisondeshimalayas.org](http://www.maisondeshimalayas.org)) is a small non-profit association based in Northern France, created in 1992 by a group of friends further

to their visits in various parts of the Himalayas. The aim of the association is to carry out social and development projects for the benefit of needy communities in mountainous areas of Nepal and India, with a focus on education (through individual sponsorship or specific projects), medical support, agriculture and local development. All active members of the association are involved in the various projects on an entirely benevolent basis.

MdH has been present in Himachal Pradesh since several years by way of sponsorship programmes for the Tibetan refugees in Dharamsala, Bir, Chauntra (Dharamsala sponsorship commission), but also in favour of local children of Kullu valley, Lahaul-Spiti, Kinnaur and other remote areas (Manali sponsorship commission). Several medical urgency actions have been carried out by the association since its creation. Since 2004, an alternative educational programme is providing primary school education to nomad children of a Rajasthani community (the "shilajit" people) settled in Manali from April to November. Dominique Dufau, Vice President of MdH, follows projects in Manali every year from June to October.

*HPVHA and MdH heartily welcome:*

- (3) any institution or individuals willing to be involved in the Handimachal project, by way of training, skill sharing, practical or financial support, etc., who may reveal themselves during the course of the project, for the sole benefit of the disabled people of Himachal and of the local community as a whole;
- (3) the people of Himachal Pradesh, whether or not impaired, wishing to reduce the handicap originated by "the non recognition of the existence of disabled persons, their exclusion from society and by the non provision of services to meet their needs".

## **A – THE HANDIMACHAL PRELIMINARY SURVEY**

As a condition precedent to the implementation of the Handimachal programme, a preliminary survey was carried out in the Kullu block of Kullu district in January and February 2007, with the objective of assessing the real number of disabled people, the proportion of disability types and degrees, their medical status and knowledge, various data concerning their living conditions and needs, i.e. gathering the maximum data available in order to study the feasibility and scope of the programme.

### ***A.1 Presentation of the methodology, conditions of realization of the survey***

#### ***A.1.1 Surveyed area***

The selected area for this survey was the Kullu block of Kullu district.

*Please refer to Appendix 2 for a full description of the surveyed area.*

## ***A.1.2 Methodology and conditions of the survey***

Methodology:

The methodology selected for this survey was based on the involvement of the power groups (panchayat pradhans, school teachers, women and yuvak mandals). After collecting information from the village pradhans about those who were disabled in their village, the affected households were systematically visited by the volunteer team (students from Sociology University, Shimla) and data were collected. A systematic door-to-door survey was considered too time-consuming and expensive due to the isolation of many houses in this hilly environment. In total 70 panchayats were covered by the various teams over a period of 35 days.

Discussion on the methodology and choice of surveyors:

On a community point of view, the selected methodology allowed the social actors of villages ("power force") to become actors in the project right from the beginning.

The choice of surveyors is a matter of discussion, as the University students recruited for the survey had no medical background. It was evidenced during the survey this was not really a drawback as the survey could produce a realistic image of problems met by families (as far as the status of disability itself is concerned but also on the ignorance and misunderstanding of the nature and cause of disability), image which might have been distorted by too premature medical interpretations from surveyors. Such strictly medical study will only be possible within a structure such as the future Handimachal Centre, with trained specialists and appropriate evaluation tools.

On the sociology point of view, this survey also provides a rather faithful snapshot of village life in the Kullu block, notably concerning the situation of women in rural areas, living conditions, the persistence of castes, the presence or not of efficient social workers, etc. Such aspects provided an interesting study item for the concerned students.

Tools for data collection:

1. A close ended questionnaire was prepared to collect the relevant data.
2. An informal interview technique including both the direct interview method (interviewing the disabled person concerned) and indirect interview (speaking to parents or relatives of the disabled) was adopted to collect information.
3. Focus group discussions (FGD) were conducted with the persons with purpose of getting in depth information about the disabled and the causes that led to disability.

Procedure for data collection:

Visits to the Kullu block were made by 15 volunteers (students from the University of Social Sciences, Shimla) who were divided into 5 groups comprising of 3 members each. As the first step, the BDO was approached and with his support a block map and the list of various panchayats and villages under each panchayat were procured. He was also approached to intimate the panchayat pradhans about the survey work and its purpose.

BDO, panchayat pradhans and common people were assured that the information collected will be used for the betterment of the underprivileged and the survey data would be submitted to the government.

### **A.1.3 Experiences from the survey**

- ü Most of the respondents were curious to know why they were being interviewed.
- ü Majority of the respondents reacted, "why are you asking unnecessary questions? You will do no good to us. Previously also people have come to collect information and had made false promises."
- ü Literate respondents were cooperative during the interview.
- ü It was difficult to interview the illiterate and semi-literate persons, most of the time was spent to make them understand the questions.
- ü Female respondents were reluctant to respond, they insisted on the presence of male members.
- ü Elderly people of the village & village pradhans were found to be very cooperative during the interviews.
- ü Parents of disabled children were eager to know about the outcome of the survey in terms of the opening up of special schools for the children.
- ü There were 22 questions in the questionnaire, it was considered to be very lengthy. The respondents were not generally willing to give adequate time for completing the questionnaire.
- ü There were problems faced answering the question on special devices needed - not many of the disabled were using any devices due to poverty or lack of advice from doctors. As a result, many were not using any devices even when they were necessary. Hence the answers noted for this question were often not reflective of the true extent of their disability.
- ü A majority of the disabled were not registered at their district welfare office.

### **A.1.4 Analysis of collected data**

Data obtained were analyzed quantitatively and qualitatively. The Survey Analysis Report (Appendix 3) was issued by Mrs Sylvie Tison (member of MdH, specialist in medical statistics in the University Hospital Centre of Bordeaux, France), and Dominique Dufau on the basis of data recorded under EPI DATA software by two data operators in Shimla. The realization of the data sheet form was carried out by Sylvie Tison and her students in concomitance with the finalisation of the questionnaire so as to match the questionnaire and provide some cross-checking possibilities of recorded data.

Within the Kullu block, a total of 1,242 interviews of disabled people (or their families) have been recorded under EPI DATA software, controlled and cross-checked in order to provide data suitable for analysis.

## **A.2 Presentation and discussion of results**

Summary of results:

The survey revealed that a significant number of people living in Kullu block (at least 1.1% of the population for this block) suffer from one or multiple disabilities. Most of the people declare to be suffering from physical, eye and hearing problems.

Overall distribution of disability types in Kullu block:

Types of disabilities	Number	Distribution
Physical	558	44.9%
Multiple	220	17.7%
Eye	185	14.9%
Hearing	115	9.3%
Speech	96	7.7%
Mental	68	5.5%
Total	1,242	100.0%

The majority appear to have developed disability after birth. A low level of awareness regarding health and hygiene amongst the people has been highlighted by the survey. Illiteracy and economic backwardness are other challenging issues.

*Please refer to Appendix 3 for detailed Disability Survey Report for Kullu block.*

Discussion of results:

On the basis of the official population figure published by the government for Kullu block (1,14,240 persons) further to the 2001 census, the percentage of disabled persons which results from the survey amounts to 1.1%, as opposed to the average percentage of 2.6% for Himachal Pradesh resulting from the 2001 census. Discussions held with government representatives further to the survey reveal that (1) the complex administrative zoning could not allow a clear counting of the population of Himachal Pradesh during the 2001 census and that (2) the "blind" counting of people judged as "disabled" by census agents may not be relied upon and that the average of 1.1% to 1.3% is far more realistic.

The need for information (both on medical and social levels) of disabled people and their families is also clearly evidenced by the survey.

## **A.3 Observation mission in Kullu block**

A further observation mission on the field was carried out during three days (third week of August) including two French occupational therapist and physiotherapist who decided to volunteer in the Handimachal project, together with Dominique (MdH) and members of the HPVHA team. The aim of such mission was to visit a limited number of selected families in order to:

ü observe the living conditions of disabled persons within their home and village,

- ü listen to problems faced and wishes expressed by disabled persons and their families,
- ü assess whether services contemplated by the Handimachal project will be in due correlation with expressed or underlying needs.

*A full report of this observation mission is attached as Appendix 4.*

## **B – THE HANDIMACHAL CENTRE, A PILOT PROJECT IN HIMACHAL**

The programme contemplated by MdH and HPVHA is based on the following objectives and concepts:

### ***B.1 Purpose and missions of the Handimachal Centre***

- ü Creation of a centre dedicated to disability, comprising a team of medical experts, an information bureau for the families and local social workers, a temporary reception centre for visiting families, a training centre for local medical actors.
- ü An important point: the Handimachal Centre is not destined to host handicapped children for long stays or to replace the families in the giving of care and looking after the children, as the philosophy underlying the Handimachal project is based on community based rehabilitation (CAHD, Appendix 1).

#### *Medical objectives:*

- ü To provide the families with a medical diagnosis for the disability child, a medical programme adapted specially for the child and an estimate of the projected future progress of the child.
- ü To educate the mothers (in particular) on the actions and attitudes which will benefit the child's health, by using the services of occupational therapists.
- ü To direct the children who are not able to stay within the family because the handicap is too extreme or difficult to cope with, to specialised centres (outside the region).

#### *Objectives in the field of education and integration:*

- ü To train specialists in the field of disability sciences (physiotherapists, occupational therapists, orthopaedists..) in the Handimachal Training School, in order to attract students after 10+2 to such "new" professions, teach them the techniques and attitude liable to reduce the handicap which impaired persons are facing in

society. Studies and diploma would be sanctioned by the RCA (Rehabilitation Council of India).

- Ü To teach the parents how best to cope with their child's handicap in the home, to evaluate on the spot how to make the child's life easier and to respond to its specific needs.
- Ü Making the local social workers aware of the different types of help that they can provide to the children and adults concerned and their families (on medical, material and legal levels).
- Ü To make sure that local government primary schools (or private, if possible) integrate disabled children and adolescents. The emphasis will be given to training of teachers in villages (by way of workshops or visits of occupational therapists within the schools) in order to help them identify a specific teaching method adapted to each specific disabled child.
- Ü Providing material assistance (wheelchairs and other equipment) and financial help, where possible, for certain cases.
- Ü Ensuring that the specific rights provided for by Indian law to disabled people are accessible to people with disabilities in the area, in order to facilitate an independent lifestyle, in particular with regards to access to employment. A special care will be taken towards disabled women, who face double discrimination based on gender and impairment.
- Ü At a later stage, if feasible: teaching manual or other (for example, computer) skills, to the adolescents, in order to promote personal development and integration into the peer group.

*Final objective:*

- Ü Bringing about the intervention of local government in order to continue the process, on a medium term basis (until the end of 2012), in order to regulate this initiative and to enable the maximum number of people to benefit from it.

## **B.2 Characteristics of the future Handimachal Centre**

The main characteristics of the Handimachal Centre, as foreseen at the present stage of discussion, still open to improvement, are set below.

### **B.2.1 Location and contemplated structure of the centre**

It is contemplated to locate the Handimachal Centre nearby Kullu town, due to the town accessibility, transportation facilities and mild climate in winter.

At the present stage of discussion and planning, it is contemplated that the building would comprise 10 rooms in the beginning, including:

*For the information mission of the Handimachal Centre:*

- ü one large waiting room with information posters and literature for the public, with information counter

*For the medical mission of the Handimachal Centre:*

- ü one consultation room to be used by doctors and visiting specialists
- ü one large room with necessary equipment for physical rehabilitation

*For the training mission of the Handimachal Centre:*

- ü one meeting & resources room, to be also used as administration office and training room for local medical staff and social workers
- ü two rooms to be used as classes for the Handimachal Training School (physiotherapy and occupational therapy training school) (more rooms to be added when needed in due time)

*For general purposes:*

- ü one store room
- ü one canteen with attached kitchen (for students, staff, visitors)
- ü toilets, bathroom
- ü in a later stage: two or three studio/rooms for visiting doctors and one/two rooms for visiting disabled persons, with attached bathrooms.

The building would be fully designed as to allow easy access to wheelchairs, to physically challenged and visual impaired persons. In this respect, a flat and even plot of land would be more appropriate for the correct design of the building.

The Handimachal Training School: It is contemplated to open a medical school to train physiotherapists and occupational therapists (after 10+2) in order to attract local (and non local) students to this profession and better serve the needs of disabled persons. The programme and diploma would be sanctioned by RCA. School fees would furthermore partly ensure the sustainability of the center.

### ***B.2.2 Perspectives in terms of residing staff***

This subject is still under study and discussion with various professionals and the following solutions are being envisaged at the moment:

One local general practitioner and one hospital specialist doctor would be attached to the centre, under special contract terms, and would provide consultation services in the centre 3 or 4 days a week.

One occupational therapist and one physiotherapist (in the beginning) would also be hired for the centre and would some days work in the centre and on other days in disabled people's homes (upon request). It is most important that the rehabilitation services provided in the centre may also be offered within the families, as many disabled persons will not be able to come to the centre for regular treatment; many adjustments may be done in the houses in order to improve the every day life of disabled persons and reduce the impact of disability.

Non medical staff would also be hired for the centre (one secretary/receptionist, one driver, one caretaker/cleaner, one cook if a canteen is to be opened). Priority would be given to disabled or impaired candidates whenever possible.

For the Handimachal Training School, teachers will be hired to provide teaching in occupational therapy and physiotherapy.

Salaries would be budgeted in the frame of the project.

### ***B.2.3 Contemplated medical partnerships (in India and from Europe)***

One of the specificity of the Handimachal center would be to organize partnerships with some national and foreign hospitals or institutions specialized in disability rehabilitation, so that specialists in physical or mental disability and mental illness may come by turns to the centre for 2-3 months specific missions (if possible on a voluntary basis), eventually under RCI's cover. The aim would be to provide as large service as possible throughout the year and respond to the needs of most situations<sup>1</sup>.

### ***B.2.4 Prosthesis service***

The necessity of acquiring a stock of specific medical equipment and prosthesis within the Handimachal center (and hiring a prosthesis technician) is still under study and will be further discussed with various organisations. This service could also be provided by way of temporary recurrent missions or in cooperation with existing facilities in Himachal (Sundernagar).

### ***B.2.5 Perspectives in terms of financial needs (both for the creation of the centre and for its sustainability)***

At this stage of the project, it has not been possible yet to assess the total budget for the implementation of the Handimachal project, which will greatly depend on the availability of a land near Kullu, designing of the building, training possibilities for the

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<sup>1</sup> Including the assessment by psychologists of potential impairment among « slow » learners – this need is expressed by some school principals who are denouncing the absence of psychological tests for students facing unusual difficulties.

original staff members, salaries of teachers, types of medical partnerships to be organized, etc.

Once these conditions will be more clearly assessed, and within a period of 12 months, MdH and HPVHA will establish a provisional budget (1) for the construction of a building and (2) for the daily operation of the Handimachal center and school in view of its sustainability.

In the meanwhile, MdH and HPVHA will identify and contact various institutions (both in France and in India) liable to support the project financially. They will collect the necessary application forms before end of June 2008, prepare paper work for the filing of grants to be made early autumn 2008 with the selected/potential funding institutions.

The question of fees

The question of medical fees is of course of concern in this project and it is contemplated that consulting disabled persons should pay a nominal fee to the residing doctor and to occupational therapists (when acting in the center or within families), so as to cover part of staff expenses and add credit to the service provided by the centre. On the other hand, all information and training would be provided freely.

In the Handimachal Training School, fees to be paid by students will be applied after agreement of RCA.

### ***B.2.6 Short-term perspectives (handing over to a local institution)***

MdH and HPVHA are planning to manage together the centre and its associated programmes during a period of three years.

At the end of 2012 (or earlier according to the progress of the project), MdH and HPVHA would carry out the total transfer of responsibility and property to the local government or to a local NGO.

## **CONCLUSION : SOCIAL IMPACT, PERSPECTIVES IN THE LONG TERM AND REGIONAL SCOPE OF THE PILOT PROJECT**

"It is obvious (although difficult to estimate precisely) that [the existence of the negative cycle of impairment, disability and handicap has a tremendous cost](#), primarily in terms of its social impact:

- ü cost of minimizing the risk of impairment,
- ü cost of providing assistance for people with impairments,
- ü cost of providing assistance to disabled persons,
- ü cost of eliminating barriers to assistance and inclusion.

It is not possible to totally eradicate disability nevertheless [the handicap faced by disabled or impaired persons may be reduced resulting in social and economical benefits](#):

- Ü value of increased production by disabled persons,
- Ü value of increased production by families and caregivers,
- Ü value of production by people whose impairments do not become permanent,
- Ü social benefits of improving the quality of life of disabled persons,
- Ü social benefits of preventing needless, premature deaths,
- Ü social benefits of improving the quality of life of family members.”<sup>2</sup>

Considering the novelty of the Handimachal project and its expected impact on the disabled population of Kullu district, MdH and HPVHA wish to explore all possibilities in terms of medical support, education, technicality, cooperation, community integration, efficiency and sustainability so that the Handimachal Centre may become a [pilot initiative in the field of disability rehabilitation in Himachal](#).

The training of disability professionals in the [Handimachal Training School](#), apart from increasing the degree of awareness in the community and improving the quality of life of disabled persons and their families, will also provide new job opportunities in Himachal Pradesh.

It is expected that the geographical scope of the Handimachal Centre may [rapidly extend to neighbouring districts](#) and, possibly, regions. If relayed by proper governmental impulse, this initiative could possibly give birth to similar programmes for the benefit of the whole population of Himachal Pradesh.

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<sup>2</sup> Extract from « Understanding Community Approaches to Handicap in Development (CAHD) », Handicap International, March 2001

## APPENDIX 1 - Key Terminology

(extract from "Disability in Development – Experiences in Inclusive Practices",  
Handicap International & Christian Blind Mission, 2006)

### Community Approaches to Handicap in Development

**CAHD implies: Community** – people, their families and the organisations that influence their daily lives

**Approaches to** – the two-way, interactive relationship within communities needed to change attitudes, so that people with disabilities will be included and have access to services and assistance that will minimise their disability and maximise their personal development

**Handicap** – not recognising the existence of people with disabilities, excluding them from society, and not providing services to meet their needs

**In Development** – including people with disabilities in the continuing processes: of increasing personal freedom; and, of sharing in a more equitable distribution of the world's resources.<sup>1</sup>

### Community Based Rehabilitation

CBR is a strategy within general community development for the rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services.<sup>2</sup>

### Disability

Disability summarises a great number of different functional limitations occurring in any population, in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.<sup>3</sup>

### Impairment

Impairment is a loss or abnormality in body structure or physiological function (including mental functions).<sup>4</sup>

### Inclusion

Inclusive development is about respecting the full set of human rights of every individual, acknowledging diversity, eradicating poverty and ensuring that all people are fully included and can actively participate in development policies and practices. In other words, inclusive development ensures that disabled people are recognised as rights-holders who must be actively engaged in the development process, irrespective of disability, age, colour, sex, race, social origin, nationality, property, birth, ethnicity, religion, or other status and that development institutions, policies and programmes must take into account and be assessed in accordance with their impact on the lives of disabled people, and are consistent with the promotion and protection of internationally recognised human rights.<sup>5</sup>

### Rehabilitation

Rehabilitation refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence.

Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. Instead it includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation.<sup>6</sup>

- 1 Adapted from Handicap International, Christoffel-Blindenmission and Centre for Disability in Development. 2001. *Understanding Community Approaches to Handicap in Development (CAHD)*. Lyon: Handicap International.
- 2 International Labour Organization, United Nations Educational, Scientific and Cultural Organization, and World Health Organization. 2004. *CBR – a strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities – joint position paper 2004*. Geneva: World Health Organization.
- 3&6 United Nations. 1993. *The Standard Rules on the Equalization of Opportunities for Persons with Disabilities*.
- 4 World Health Organization. 2001. *International classification of functioning, disability and health (ICF)*. Geneva: World Health Organization.
- 5 International Disability and Development Consortium. 2005. *Inclusive Development and the Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*.

## APPENDIX 2 – Description of Kullu block of Kullu district

### BLOCK PROFILE

DESCRIPTION	DETAILS
Year of creation of block	1962
Total area(sq. Km)	148.85
Name of assembly Consistency	Kullu
<b>Population (2001) Census)</b>	
Total	114240
Male	59542
Female	54694
Sex ratio	918
<b>Gram Panchayats</b>	
No. of Gram Panchayats	70
No of backward Panchayats	10
<b>Education</b>	
Anganwaris	89
Primary schools	230
Middle schools	31
High schools	13
Senior secondary schools	8
Colleges	1
ITI	1
<b>Health</b>	
PHC	4
CHC	1
Sub –centres	26
Hospitals	1

Kullu district is located between 31°58'00" North Latitude and 77°06'4" East longitude. On the North and North-East, it is bounded by Lahaul Spiti and Kangra districts, on the east and south-East by Kinnaur and Shimla district. Climate of the district is cool and dry. The district receives moderate rainfall and bulk of it is received during the months of July, August, December and January. The wettest month is August.

The rock type found in the district are phyllite, slate, quartzite, limestone, schists and granites. The bulk of the population of the district comprises of Hindus followed by Buddhist and a sprinkling of others belonging to Sikhs, Jains, Chirstains. Hindus are Rajputs(Kanets,Khasas), Brahmins, Khattris and scheduled castes.Scheduled castes mostly comprises of Koli, chamar and dumna.

The economy of the district is mostly agrarian. The agro-climatic conditions in the district vary considerably. Due to agro-climatic conditions, the district is most suitable for the growing of citrus and temperate fruits. Since last many decades, Kullu apples are well known throughout the country.

Next to agriculture, livestock is the most important source of income. Every household in the district invariably keeps a few cows or buffaloes, sheep, goats, pigs and ponies.

Among the industries that exist in the Kullu valley are the shawl and handloom industry. Another thing which has become extremely popular is the Kullu cap. Besides these, boarders with interesting designs are being produced for use in sarees and other dresses. Before shawls, the locals used to weave pattus and patties which were used for making local dress. One little known fact is that tea was grown in Kullu. It was said to have an excellent flavour and aroma but yield was low, cost of cultivation quite uneconomical, competition from outsiders and transportation to long distances was a problem.

For the purpose of the survey the block was divided into five valleys as follows:

- Lug Valley
- Gudsa valley
- Oat Valley
- Manikaran Valley
- Local Valley

#### The Lug valley

Lug valley is geographically very difficult as most of the area is hilly, it requires walking as no transportation facilities are there. It takes approx. two hours to reach the road from the valley. Casteism is very much prevalent there. This gets confirmed from the displays exhibited there that said " beedi, cigarette, lower caste people are prohibited in the area". People of the valley are economically poor. Though only khadi and apple are their source of livelihood their production is at a subsistence level. There is low educational level and standard of living is also low.

#### The Manikaran Valley

This valley is a known tourist place. People are comparatively rich. Most families have persons working as guides, taxi operators and sellers of handlooms. Economically the whole valley is well off, due to its tourist place status leaving aside tapini, puji, kaswari and danogi that are agrarian and backward. People of the valley are stereotypes and religious in the sense that they have less faith in the modern technology and would prefer to go by some existing believes. This acts as a major hindrance to the overall development of the valley.

#### The Gudsa valley

People are economically sound, their standard of living is comparatively good, most people own enough land for agriculture and some people are engaged in government jobs. Manjhali Panchayat is a rich panchayat. People of the valley are very educated and are holding high ranks in various government departments. The other face of the valley is that it has huge drinking water and transportation problems.

#### The Oat Valley

Compared to the other valleys in the block, this valley has comparatively an aware community. People are aware of health and hygiene issues. Habitat is scattered and it requires several hours walk to reach a destination. Among the panchayats, Raila panchayat has no health centre, Devgarh has no middle and high schools and no post offices. Some panchayats have good natural resources, for example Devgarh panchayat

has a slate natural resource and Bhalan II a golden stone crusher that is being used for construction purpose. Farmers also grow charas in their fields which is easily sold out at higher rates. Hatt is a urban panchayat with all basic amenities at place. Masgoan panchayat is half urban and half rural. The other panchayats are hilly and they are economically backward.

### Local Valley

Local valley is a very beautiful valley, full of greenery and natural herbs. This area has black and red stones. Like other valleys this area also suffers from casteism. Transportation is another persisting problem of the valley. Women and children are making extensive use of smack which leads to socially volatile situation.

### PROBLEMS OF KULLU BLOCK

- ü Caste system is prevalent.
- ü Girls are married before 18 years of age.
- ü Lack of Social security.
- ü People are less aware of issues related to health and hygiene.
- ü Sterotypeness in behaviours are common.
- ü Extensive use of local drugs by all age groups .
- ü Some panchayats have drinking water problem.
- ü Lack of proper sanitation facilities.
- ü Educational level is low.
- ü Transportation problem persists.

## APPENDIX 3 – Disability Survey Report for Kullu block of Kullu district (January- February 2007)

### 1. GENERAL CHARACTERISTICS

The checked files gather information on **1,242 handicapped people**, that is around 1.1% of population of Kullu block (based on 2001 census: 1,14,240 inhabitants)

The present study is focussing on the following disability types, which are slightly different from the ones categorised by the PWD Act, 1995:

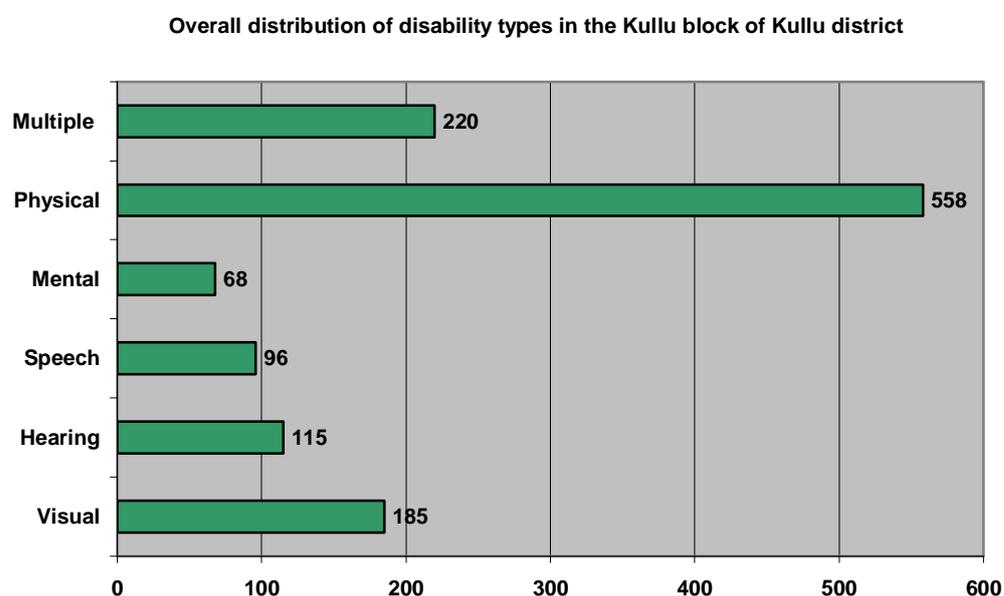
- “Eye”: blindness and low vision
- “Hearing”: Hearing impairment
- “Physical”: Loco motor disability
- “Mental”: Mental retardation and mental illness
- “Speech” (not categorised by PWD Act)
- “Multiple”, i.e. combination of several of the above disability types
- (Leprosy-cured has not been assessed by this study)

Important remark: All percentages are calculated on the basis of a specific “N” value relevant to each analysis.

#### 1.1 Overall distribution of disability types

Types of disabilities	Number	Distribution
Physical	558	44.9%
Multiple	220	17.7%
Eye	185	14.9%
Hearing	115	9.3%
Speech	96	7.7%
Mental	68	5.5%
<b>Total</b>	<b>1,242</b>	<b>100.0%</b>

The Handimachal project - Kullu block survey - January-February 2007



## 1.2 Total population of disabled according to type of disability and gender

Among the 1242 disabled censused 754 are male (60.7%) and 488 female (39.3%). As a comparison, the gender wise distribution of population in Himachal Pradesh is 54% for men and 46% for women.

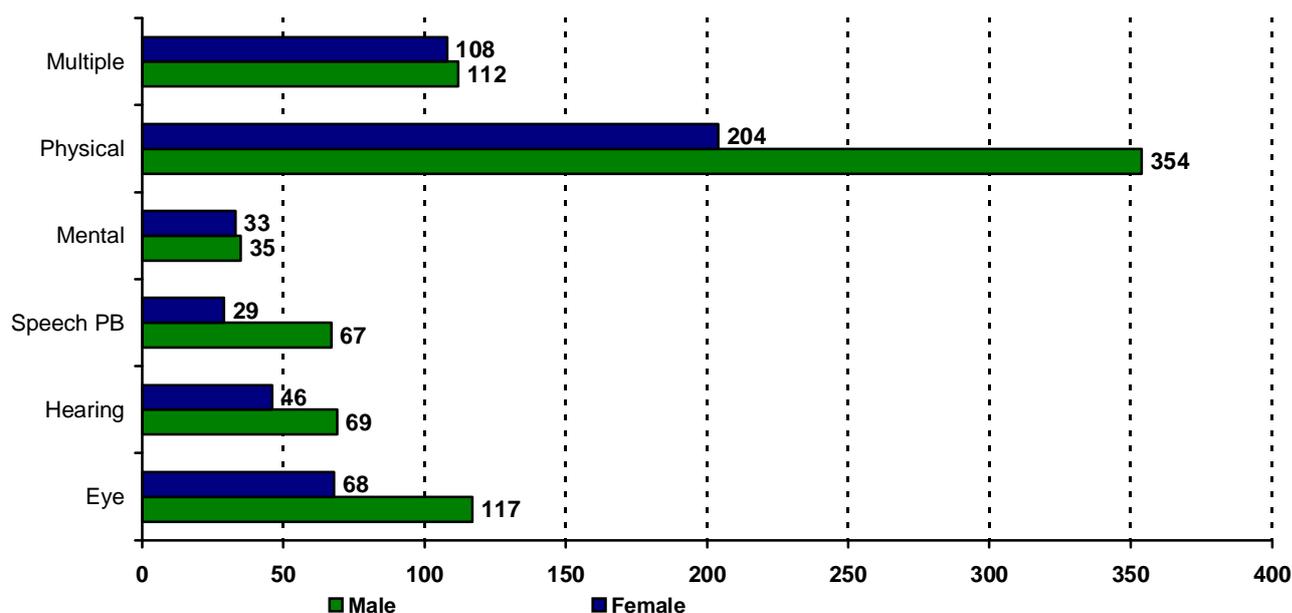
**Out of 10 disabled people, 6 are men, 4 are women.**

Disabled according to type and gender. (N=1242)

Type of disability	TOTAL		MALE		FEMALE	
	Number	%	Number	%	Number	%
Eye	185	14.9	117	15.5	68	13.9
Hearing	115	9.3	69	9.2	46	9.4
Speech	96	7.7	67	8.9	29	5.9
Mental	68	5.5	35	4.6	33	6.8
Physical	558	44.9	354	46.9	204	41.8
Multiple	220	17.7	112	14.9	108	22.1
<b>Total</b>	<b>1242</b>	<b>100.0</b>	<b>754</b>	<b>100.0</b>	<b>488</b>	<b>100.0</b>

The Handimachal project - Kullu block survey - January-February 2007

Disability according to type and gender (754 Males and 488 Females)



The Handimachal project - Kullu block survey - January-February 2007

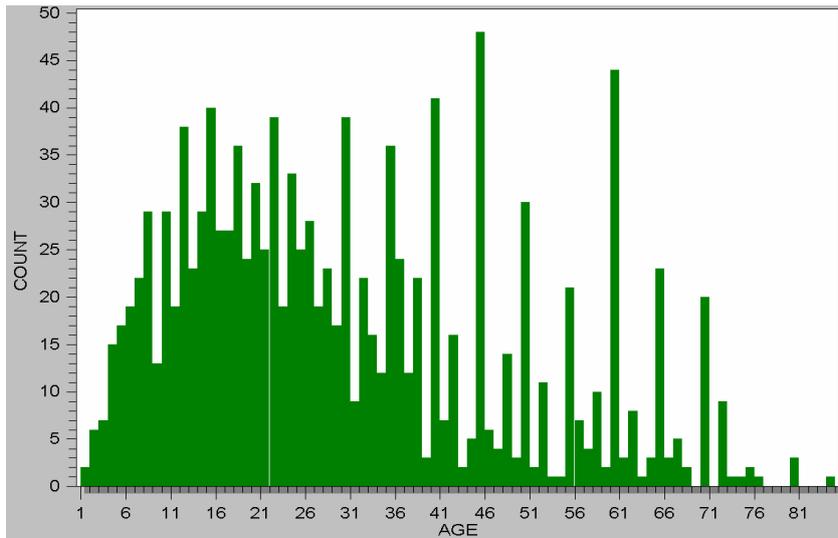
## 1.3 Disability distribution according to gender and age

The proportion of disabled men is higher in adults than in children and young.

Age group	Male		Female		All	
	Number	%	Number	%	Number	%
Under 18 years old	223	58.8%	156	41.2%	379	100%
18 years old and over	531	61.5%	332	38.5%	863	100%
All	754	60.7%	488	39.3%	1242	100%

On graph showing disabled by years of age, it clearly appears that age is "roughly" known past mid-life : 40, 45, 60, 70 are much more popular ages than 39, 43, 69 ... it is classical in this kind of surveys, in all countries, and does not affect the validity of results.

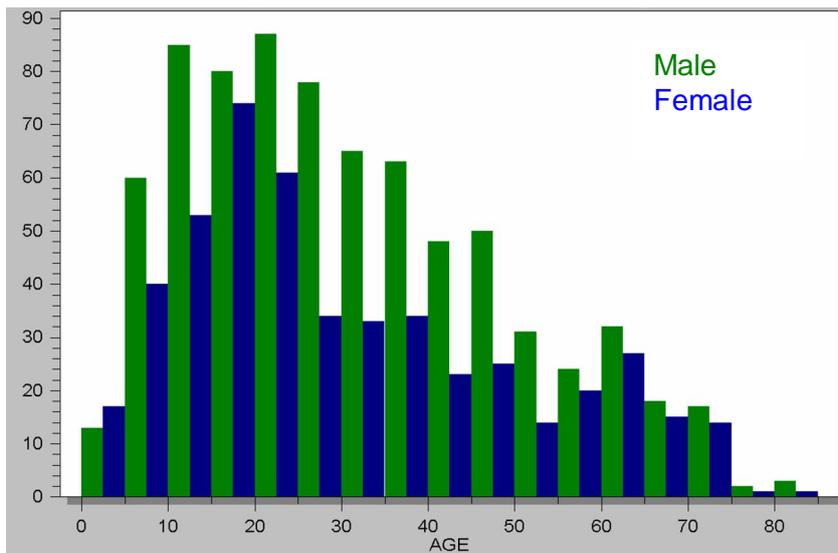
Disabled according to age in years. (N=1242)



The Handimachal project - Kullu block survey - January-February 2007

The following graph of ages by gender shows a majority of disabled male at all ages except before 5 years old.

Disabled according to age and gender. (N=1242)



The Handimachal project - Kullu block survey - January-February 2007

#### 1.4 Disability distribution according to place of living

93% of disabled of Kullu block live in rural areas. As shown on table, the gender distribution of disabled people is relatively the same in rural and in urban areas of the block.

Disabled according to gender and place of living N=1242.

Place of living	Male		Female		All	
Rural	701	60.9%	451	39.1%	1152	92.75%
Urban	53	58.9%	37	41.1%	90	7.25%
All	754	60.7%	488	39.3%	1242	100%

The Handimachal project - Kullu block survey - January-February 2007

## 2. CHARACTERISTICS OF DISABLED CHILDREN

(under 18 years old) [N=379]

### 2.1 Types of disabilities

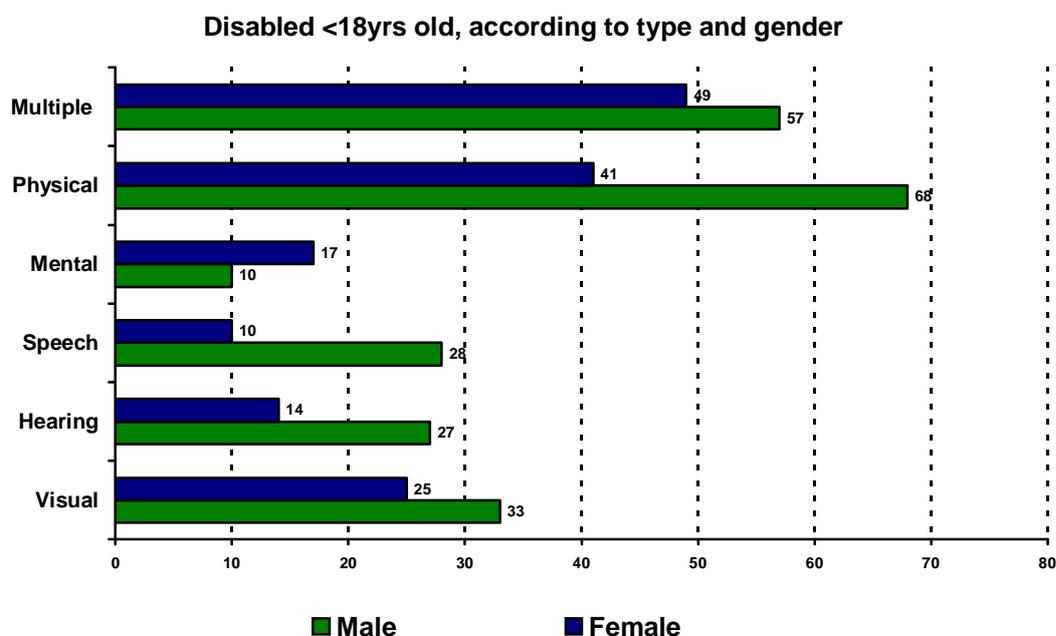
The proportion of children suffering from the different types of disabilities is slightly different in disabled boys and disabled girls, physical impairment being the most frequent in both genders.

None of these children has been declared combining both hearing and speaking problems, which may reveal that the medical assessment of hearing and speaking impairment may not have been carried out jointly.

Some files contain the diagnosis of “polio” as being the source of disability, not detailing if it has been assessed by doctors or said so by the parents. This item “Polio”, which could also be a misclassification of cerebral palsy, concerns at least 3 children under 7 years old, 4 between 7 and 11, and 5 between 12 and 17. On the other hand, numerous other polio cases are certainly part of the “physical handicap”.

Disabled under 18 years old, according to type of disability and gender. N=379

Disability	Disabled boys N (% of 205)	Disabled girls N (% of 157)	Total disabled < 18 y. N (% of 379)
Eye	33 (14.8%)	25 (16.0%)	58 (15.3%)
Hearing	27 (12.1%)	14 (9.0%)	41 (10.8%)
Speech	28 (12.6%)	10 (6.4%)	38 (10.0%)
Mental	10 (4.5%)	17 (10.9%)	27 (7.1%)
Physical	68 (30.5%)	41 (26.3%)	108 (28.8%)
Multiple	57 (25.6%)	49 (31.4%)	106 (28.0%)



The Handimachal project - Kullu block survey - January-February 2007

## 2.2 Study of disability symptoms/criteria among children under 18 years

Based on information about what the disabled children “cannot do” (when information has been provided), the following data are roughly available:

Children between 1 and 5 years old (inclusive):

Relevant activities / things that the disabled child cannot do	Reported cases in 1-5 y age group	% for 1-5 y age group (N=47)
Breath properly	2	4,30%
Dress up alone	1	2,10%
Control emotions	1	2,10%
<b>Hear</b>	<b>0</b>	
<b>Hear properly</b>	<b>0</b>	
Keep balance	2	4,30%
Memorise	1	2%
See	2	4,30%
See from far	1	2,10%
<b>Talk</b>	<b>9</b>	<b>19,10%</b>
<b>Talk properly</b>	<b>2</b>	<b>4,30%</b>
<b>Walk</b>	<b>5</b>	<b>10,60%</b>

Children between 6 and 18 years old (inclusive):

Relevant activities / things that the disabled child cannot do	Reported cases	% for 6-18 y age group (N=315)
Breath properly	2	0,60%
<b>Carry</b>	<b>9</b>	<b>2,90%</b>
Digest properly	1	0,30%
Dress up alone	3	1,00%
Eat alone	4	1,30%
Control emotions	5	1,60%
<b>Hear</b>	<b>14</b>	<b>4,40%</b>
<b>Hear properly</b>	<b>12</b>	<b>3,80%</b>
<b>Keep balance</b>	<b>19</b>	<b>6,00%</b>
Memorise	8	2,50%
Mix with people	3	1,00%
problem with people	4	1,30%
Play with other children	3	1,00%
<b>See</b>	<b>10</b>	<b>3,20%</b>
<b>See from far</b>	<b>9</b>	<b>2,90%</b>
Sit up	3	1,00%
Feels strong pain	5	1,60%
<b>Talk</b>	<b>49</b>	<b>15,60%</b>
<b>Talk properly</b>	<b>10</b>	<b>3,20%</b>
<b>Use arms</b>	<b>9</b>	<b>2,90%</b>
<b>Walk</b>	<b>20</b>	<b>6,30%</b>
Wash	3	1,00%
Write or draw	3	1,00%

The Handimachal project - Kullu block survey - January-February 2007

In the 1-5 years age group, speech impairment is important, as well as locomotion impairment (if linked, they could find their origin in cerebral palsy following a problem during delivery).

Strikingly, there seems to be no control of hearing impairment linked to speech impairment (which could help determine whether language impairment or mental problem might not be due to hearing deficiency).

In the 6-18 years age group, hearing problems are now reported (probably highlighted in school) and speech deficiency is also very important.

Numerous cases of visual impairment are also reported. Locomotion problems are highlighted in this age group.

## 2.3 Origin of disability for children and adolescents

The etiology of disability was also asked to both disabled children and relatives. When unknown to them, data has been recorded under “Data not available”. The high level of non available data clearly shows the medical isolation of disabled children.

Nearly half of the disabled children or adolescents seem to be handicapped since they were born.

Disabled under 18 years old, cause of disability. N=379

Cause of disability (according to families)	Disabled boys N (% of 223)	Disabled girls N (% of 156)	Disabled < 18 y. N (% of 379)
Accident or trauma	36 (17.6%)	22 (14%)	58 (16%)
Occurred at birth	90 (43.9%)	78 (49.7%)	176 (48.6%)
Medical cause known	18 (8.8%)	12 (7.6%)	32 (8.3%)
Data not available	79 (35.4%)	44 (28.2%)	123 (32.4%)

The Handimachal project - Kullu block survey - January-February 2007

These results must be looked at carefully as for instance some "polio" cases are told to be linked to "accident" or "at birth" instead of medical cause. Other troubling findings are some cases where "disabled at birth" was associated to accident or medical cause.

## 2.4 Conditions of delivery among disabled children and adolescents

This study was conducted among children declared as "disabled by birth" (N=108) and clearly shows the **positive evolution** of delivery conditions since the last 5 years (2002), **although the proportion of home deliveries is still very high and prevailing**, as well as deliveries performed by non trained women (village "midwife" (*daai*) or village women).

Study on place of delivery by age-group for disabled children by birth

Age group	Missing data	Delivery at home	Delivery in hospital	Total
1-5 years	1	11 (64.7%)	5 (29.4%)	17
6-18 years	17	69 (75.8%)	5 (5.5%)	91

The Handimachal project - Kullu block survey - January-February 2007

Study on actors of delivery by age-group for disabled children by birth

Age group	Missing data	Local "midwife"	Village women	Trained birth attendant	Total
1-5 years	2	3 (17,6%)	8 (47,1%)	4 (23,5%)	17
6-18 years	19	6 (6,6%)	61 (67,0%)	5 (5,5%)	91

The Handimachal project - Kullu block survey - January-February 2007

## 2.5 Proportion of disabled children and adolescents living with their parents

The great majority of interviewed children and adolescents live with their parents, as there are no residential homes for such children in this area.

Disabled under 18 years old, according to whom they are living with. N=379

Living with	Male disabled N (% of 223)	Female disabled N (% of 156)	Disabled < 18 y. N (% of 379)
Parents	193 (86.4%)	142 (91.0%)	335 (88.3%)
Grand parents	1	-	1
Other people	-	-	-
Not known	11	15	26

The Handimachal project - Kullu block survey - January-February 2007

## 2.6 Proportion of disabled children and adolescents going to school

The question "Going to school or not" has been crossed with age. As very few disabled people of 18, 19, 20 years old still go to school, percentages have been calculated only among disabled under 18.

Only half of disabled children go to school, mainly when over 7 years old. Less girls go to school (41% versus 50% of boys), in every age group.

Proportion of disabled under 18 years old going to school N=379

Group of age	Disabled children	Disabled going to school
1 to 5	45	2 (4.4%)
>5 to 11	116	84 (72.4%)
>11to 18	218	108 (49.5%)
<b>Total disabled &lt; 18 y.</b>	<b>379</b>	<b>194 (51.2%)</b>

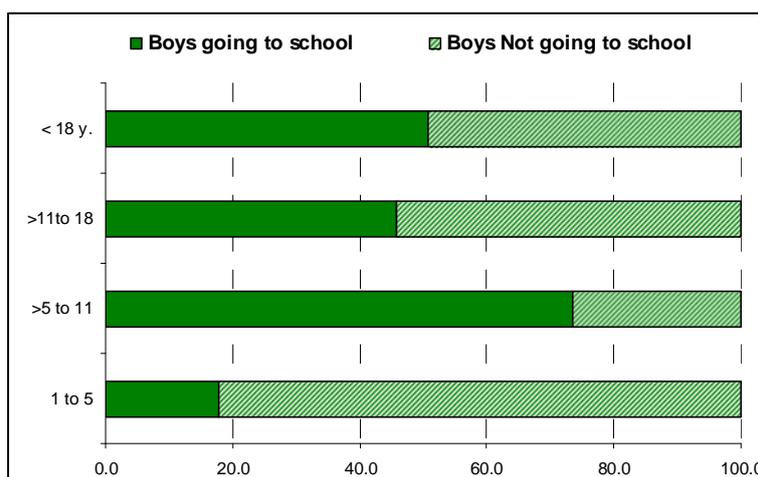
The Handimachal project - Kullu block survey - January-February 2007

Proportion of disabled children under 18 years old going to school, by gender. N=379

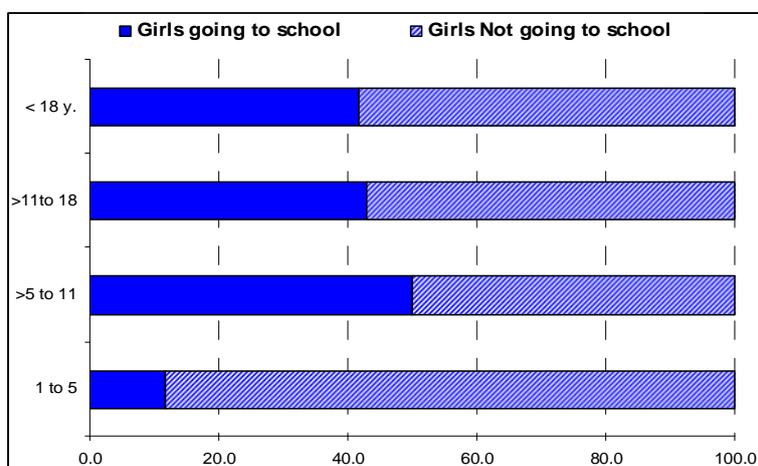
Group of age	Disabled Boys	Going to school among disabled boys	Disabled Girls	Going to school among disabled girls
1 to 5	28	5 (17.9%)	17	2 (11.8%)
>5 to 11	68	50 (73.5%)	48	24 (50.0%)
>11to 18	127	58 (45.7%)	91	39 (42.9%)
<b>Total Disabled &lt; 18 y.</b>	<b>223</b>	<b>113 (50.7%)</b>	<b>156</b>	<b>65 (41.7%)</b>

The Handimachal project - Kullu block survey - January-February 2007

Proportion of disabled BOYS (under 18 years old) going to school. N=223



Proportion of disabled GIRLS (under 18 years old) going to school. N=156



The Handimachal project - Kullu block survey - January-February 2007

### 3. CHARACTERISTICS OF DISABLED ADULTS

(18 years old and over) [N=863]

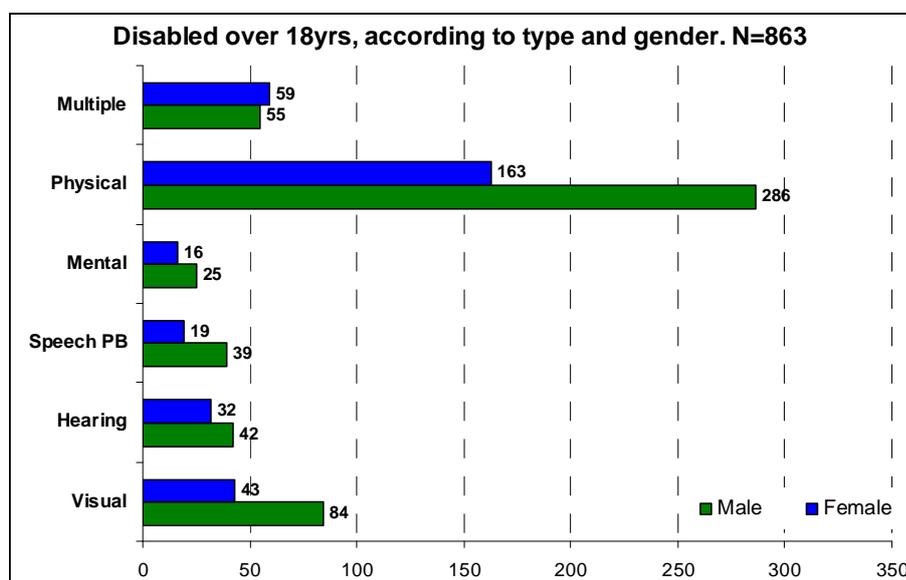
#### 3.1 Types of disabilities

Not only more handicapped male have been included in the study (see graphs by gender) but there are some differences in the types of handicaps between men and women.

Disabled adults, according to type of disability and gender. N=863

Disability type	Male disabled N (% of 531)	Female disabled N (% of 332)	Disabled ≥ 18 y. N (% of 863)
Eye	84 (66.1%)	43 (33.9%)	127 (14.7%)
Hearing	42 (56.8%)	32 (43.2%)	74 (8.6%)
Speech	39 (67.2%)	19 (32.8%)	58 (6.7%)
Mental	25 (61.0%)	16 (39.0)	41 (4.8%)
Physical	286 (63.7%)	163 (36.3%)	449 (52.0%)
Multiple	55 (48.2%)	59 (51.8%)	114 (13.2%)
<b>Total</b>	<b>531 (61.5%)</b>	<b>332 (38.5%)</b>	<b>863 (100%)</b>

The Handimachal project - Kullu block survey - January-February 2007



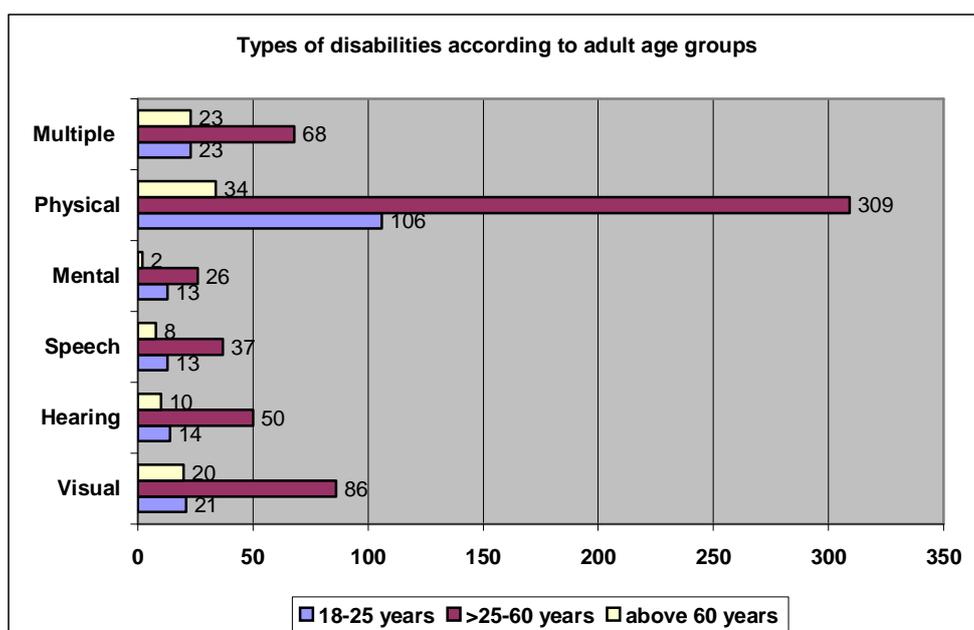
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Types of disabilities according to adult age groups (\*)

Type of disability	18-25 years		>25-60 years		above 60 years	
	Frequency	%	Frequency	%	Frequency	%
Visual	21	11,0	86	15,1	20	21,7
Hearing	14	7,3	50	8,8	10	10,9
Speech	13	6,8	37	6,5	8	8,7
Mental	13	6,8	26	4,6	2	2,2
Physical	106	55,5	309	54,1	34	37,0
Multiple	23	12,0	68	11,9	23	25,0
<b>Total</b>	<b>190</b>	<b>99,5</b>	<b>571</b>	<b>100,0</b>	<b>92</b>	<b>100,0</b>

The Handimachal project - Kullu block survey - January-February 2007

(\*) In the above table, percentages are expressed on the basis of disabled adult population for each age group (and not for the total adult disabled population). Such percentages express relative proportions of all handicap types. For example, if we consider the age group > 60 years as opposed to other age groups, the reading of results for Physical disability should take into consideration the fewer population of that age group and is not relevant when compared to other age groups.



The Handimachal project - Kullu block survey - January-February 2007

### 3.2 Study of disability symptoms/criteria among adults

Based on information about what the adults “cannot do” (when information has been provided), the following data are roughly available:

Relevant activities / things that the disabled adults cannot do (physical handicap)	Reported cases
Breath properly	4
Carry	26
Control movement	2
Cook meal	13
Digest	1
Dress up alone	7
Eat alone	5
Control emotions	4
Hear	3
Hear properly	9
Keep balance	43
Memorise	3
Mix with people	2
problem with people	1
Play with others	3
See	1
See from far	4
Sit up	6
Feels strong pain	14
Take medecines alone	1
Talk	14
Talk properly	5
Use arms	47
Walk	65
Wash	8
Write or draw	6

Relevant activities / things that the disabled adults cannot do (mental handicap)	Reported cases
Carry	1
Control movement	0
Cook meal	1
Dress up alone	2
Eat alone	1
Control emotions	1
Hear	0
Hear properly	0
Memorise	3
Mix with people	1
problem with people	1
See from far	1
Sit up	1
Take medecines alone	1
Talk	7
Use arms	1
Walk	2
Write or draw	2

The Handimachal project - Kullu block survey - January-February 2007

### 3.3 Disability level

The disability level options were : below 40% (activity is slightly difficult, can be compensated with little help), 40 to 60% (activity is difficult, important help is required) and over 60% (activity is very difficult/impossible, cannot live alone, important burden for the family).

This item is detailed in less than half of cases. It could be an indicator of a fair and comprehensive interview, considering that (1) investigators had no medical background and were not comfortable with this estimation for all type of disabilities and (2) most of disabled persons were not able to show their disability medical certificate or had none.

### 3.4 Origin of disability

The etiology of disability was also asked to both disabled adults and their relatives when necessary. When the origin of disability was not known to them, data has been recorded under "Data not available". This very high level of non available data may either be the result of memory biases or may reveal once again the medical isolation of disabled adults, who are not able to name the origin of their impairment.

More than half of disabled men declare their disability to be caused by accident or trauma, this rate is much lower with disabled women. The occurrence of disability at birth is higher for women than for men.

Disabled adults (>18 years old), cause of disability. N=863

Cause of disability (according to disabled)	Disabled males N (% of 531)	Disabled female N (% of 332)	Disabled > 18 y. N (% of 863)
Accident or trauma	271 (51.04%)	117 (35.24%)	388 (44.96%)
Occurred at birth	98 (18.46%)	80 (24.10%)	178 (20.63%)
Medical cause known	26 (4.90%)	12 (3.61%)	38 (4.40%)
Data not available	136 (25.61%)	120 (36.14%)	276 (31.98%)

The Handimachal project - Kullu block survey - January-February 2007

Again, these results must be looked at carefully as for instance some "polio" cases are told to be linked to "accident" or "disability at birth" instead of medical cause. Other troubling findings are some cases where "disabled at birth" was associated to accident or medical cause.

### 3.5 Marital status of disabled adults, by age group and gender.

Disabled adults of 18 years old and over, according to marital status and gender. N=880

Group age	Male disabled	Female disabled	Disabled ≥ 18 y
Group age 18 to 50	446	245	691
- Married	245 (54.9%)	128 (52.2%)	373 (54%)
Group age over 50	105	84	189
- Married	92 (87.6%)	77 (91.7%)	169 (89.4%)

The Handimachal project - Kullu block survey - January-February 2007

The 50 years old cut-off appears to be relevant as marital status is radically different under and over 50. Results suggest that disabled under 50 could be disabled "grown-up", being disabled since childhood and therefore less often married than disabled over 50, whose handicap (by accident or medical cause) occurred as they were already married.

### 3.6 Occupational status of disabled adults

A total of 130 handicapped adults declared they were working, **104 men** (19.58% of disabled men) versus **26 women** (7.83% of disabled women).

According to collected data, the distribution of types of employments reveals that most disabled people are self employed and that “government” employment represents 29% of employment for handicapped adults.

Type of employment	Working disabled men (W=104)		Working disabled women (W=26)		Total working disabled (W=130)	
<b>Self employed</b>	55	52.88%	14	53.85%	69	53.08%
<b>Govt employed</b>	31	29.81%	7	26.92%	38	29.23%
<b>Privately employed</b>	14	13.46%	2	7.69%	16	12.31%

When detailed, the description of jobs reveals that most disabled adults work in agriculture (20 men and 6 women), with a small number of men working as tailors (6), shop keepers (5), teachers (2), clerks (3), water carriers (3), electricians (1), jewel maker (1), home or office guards, labourers, etc., while very few women have identified jobs (2 as water carriers, 1 in computers, 1 in handicraft).

### 3.7 Device needed by disabled adults

It is not clear whether “*device needed*” means “*what does the disabled needs and already has and uses*” or “*what does he or she needs and wishes to have in order to help*”. Some details are given (“use sticks”, “wheelchair from NGO”) leading to assess the first meaning, others could mean both (spectacles, hearing machine...). This item should be clarified in further surveys in order to better assess disabled people’s needs.

## 4. OTHER SPECIFIC STUDIES

### 4.1 Study on ante natal checking vs. disability at birth

This study applies to children and young only, declared as “disabled at birth” (N=108) during the survey.

Age group	Antenatal check up (% of N)	No antenatal Check up (% of N)	Missing Data
<b>1 - 5 yrs</b>	76.50%	17.60%	5.90%
<b>&gt;5 - 18yrs</b>	38.50%	42.90%	18.70%
<b>Percentage of children disabled at birth</b>	44.40%	38.90%	16.70%

**The Handimachal project - Kullu block survey - January-February 2007**

The percentage of disabled children’s mothers having declared ante natal check up shows a strong progress for younger children as opposed to children born before 2002.

Nevertheless, the fact that such disabilities “at birth” (which may result from foreseen delivery conditions, medical status of the mother, etc.) may still occur after such medical checks is quite worrying. *This could imply that ante natal checking does not assess disability risks at the moment.*

## 4.2 Study on post natal checking vs. disability at birth

Again, this study applies to children and young only, declared as “disabled at birth” (N=108) during the survey.

Age group	Postnatal check up (% of N)	No Postnatal Check up (% of N)	Missing Data
1 - 5 yrs	70.6%	23.5%	5.90%
>5 - 18yrs	36.3%	45.1%	18.70%
Percentage of children disabled at birth	41.7%	41.7%	16.70%

The Handimachal project - Kullu block survey - January-February 2007

Figures are in line with ante natal checking results and also reflect a positive evolution of post natal checks by mothers and children.

*The fact that 23.50% of disabled children born after 2002 have not benefited of post natal checks (providing this concept was really properly understood during the survey) is highly critical, as these disabled children are the ones who really need to be medically followed right after birth.*

## 4.3 Study on disability vs. polio

The survey is also targeting on the impact of polio immunization on disability.

The following data results from a study realised on children and adolescents only, declared as “handicapped at birth” (N=108), who answered the question “*Was the child administered polio injection or not?*”.

Considering that it might not have been clear for both parents and surveyors that immunization includes both oral and injection means, this study should be confirmed in the future.

### Polio immunization among disabled children, by age group

Age group	Missing data	No vaccination	Polio vaccine declared	Total
1-5 years	1	3	13 (76.5%)	17
6-18 years	19	20	52 (57.1%)	91

The Handimachal project - Kullu block survey - January-February 2007

Results by age group show a drastic positive evolution of immunization for children born after 2002.

### Polio immunization among disabled children, by gender

Gender	Missing data	No vaccination	Polio vaccine declared	Total
Boy	14	11 (16.9%)	40 (61.5%)	65
Girls	6	12 (27.9%)	25 (58.1%)	43
Total	20	23 (21.3%)	65 (60.2%)	108

The Handimachal project - Kullu block survey - January-February 2007

Analysis by gender shows that the proportion of boys vaccinated is higher than for girls. The higher proportion of non-vaccinated girls (27.9%, as compared to boys: 16.9%) is critically

reinforced by the fact that missing data are lesser for girls than for boys and that this information can thus be considered as reliable.

#### Status of polio immunization vs. declared polio cases

Cross analysis reveals only very few cases of polio declared or polio assessed cases among disabled children (4 positive cases among 65 physically disabled children, including missing data for 20 children).

#### 4.4 Status of co-handicap within families

The survey also attempts to target the possible appearance of several disability cases within same families. Cross-analysis of questionnaire results provides the following summarised data:

- ü Among the 1,242 surveyed cases, 164 persons have declared that another disabled person exists within their family. And again, we should be cautious with such result considering the fluctuant concept of “family” and “relatives” in this area.
- ü Within this population of 164 persons, “at birth” disability prevails (33.5%), as compared to “accident” (25.6%) or “medical cause” (4.9%), taking into account that the proportion of missing data on this item is quite high. “At birth” disability may suggest that the cause of disability may be hereditary or at least that it is seen by the interviewed persons as a family problem – when such disability problem may not have any medical correlation at all (only a specific medical study could assess such connections).

Another reading of data provides the following:

- ü among the 286 disabled persons having declared a “handicap at birth”, 19.2% declare to have another disabled person within their family,
- ü among the 446 disabled persons having declared a handicap by accident, 9.4% declare to have another disabled person within their family,
- ü among the 67 disabled persons having declared a handicap due to medical cause, 11.7% declare to have another disabled person with their family.

#### 4.5 Study of benefits and pensions received by disabled persons

The Handimachal survey highlights the following facts:

Percentage of disabled persons registered with the Welfare Office:

Age group	% in age group
1 - 5 yrs	4.3%
>5 - 18yrs	9.5%
>18yrs – 25yrs	16.3%
>25yrs – 60yrs	10.8%
>60yrs	15.1%

Percentage of disabled persons receiving pensions:

Age group	% in age group
1 - 5 yrs	0.0%
>5 - 18yrs	6.3%
>18yrs – 25yrs	12.3%
>25yrs – 60yrs	12.7%
>60yrs	24.4%

Percentage of disabled persons receiving other benefits:

Age group	% in age group
1 - 5 yrs	8.5%
>5 - 18yrs	20.6%
>18yrs – 25yrs	38.4%
>25yrs – 60yrs	39.7%
>60yrs	37.2%

The Handimachal project - Kullu block survey - January-February 2007

42.9% of disabled adults say they are “followed by a doctor” (378/880), few know his/her name, most give only hospital or town name.

343 (39%) have at least one of the following benefits: transportation (182), pension (249, 28% of all disabled adults), work thanks to employment quota (16).

Only 116 (13.2%) of the total disabled adults say they are registered to the Welfare Office.

In this kind of survey a possible bias comes from people maximizing the help they need in order to get some external help (pension, medicine ...). Another bias could be minimizing problems when denying the handicap or hoping natural improvement.

#### **4.6 Interest in the future Handimachal centre**

The questions:

- ü *“Is the disabled/family of the disabled willing to come and meet specialised doctors in the Handimachal centre?”*
- ü *“Are the disabled and his/her family willing to accept the visit of occupational therapists to help improve his/her health and living conditions at home?”*

were answered “**Yes**” respectively by 98.5% and 97.7% of disabled, and there is little interest separating answers given by men or women (1% difference), children and adults.

#### **Conclusion: A need for patient and population education**

Not only this survey showed interesting data about the way of living, health conditions, specific needs, etc. of disabled persons, but also it showed the [need for both health and educational projects](#).

For instance, the number of polio cases, especially among young people, cases who could have been avoided by vaccination, and the proportion of polio immunized in this sample, are important information. People in charge of immunization program, can handle these results to motivate health professional and parents, in order to increase the proportion of polio-immunized people.

Polio is underestimated in our survey, very few of the polio-declared cases have been declared as handicap of medical source, more have been declared as accident or at birth. Without further information it is impossible to know how many polio cases have been misclassified as accident, or cerebral palsy misclassified as polio.

In addition to the number of “undefined” cases and the lack of medical and/or social information revealed by the survey (answers given as “do not know” to general or specific questions), the weak percentage of children and adults receiving social help once again highlights the urgent need of a socio-medical programme capable of:

- ü adequately assessing the nature and degree of disability of the concerned persons,
- ü helping them in claiming the relevant benefits provided by law,
- ü providing adequate medical information, training and treatment,
- ü strengthening the integration of disabled persons in the local community.

As long as people do not know more about their handicap or their relatives' one, they will not be able to ask for relevant help. Devices needed are frequently missing data, the investigator has often noted "can't say precisely", which is not surprising as they cannot even name their problem.

A population-based survey is usually the best way to cense the real needs of patients, as a large majority of the disabled people still live with their family. Going to specialized centres or schools for disabled (i.e. the school for blind people in Kullu town) would have been an efficient way of identifying patients, but not their needs when at home, and not the needs of the people too handicapped to go to school, lacking support, or not aware of the possibility of getting one, people which are the priority target of the project.

Conducted by sociologists this survey was the opportunity of collecting important data as school attendance, employment, source of income. Medical students or nurses are not used to collecting this kind of information and could have been tempted to focus on handicap "only". On the other hand they would have been more accurate to check the type and level of disability. In the future it is of major importance that social sciences still participate, as well as medicine and rehabilitation, in defining the needs of population.

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## APPENDIX 4 – Observation Mission Report on Disability in Kullu block of Kullu district (August 2007)

This observation field mission was realized to supplement the Disability Survey realised in the Kullu block of Kullu District in January and February 2007, as Phase I of the Handimachal Project.

The aim of this observation mission was to witness (with European eyes and expertise, confronted with local conditions) the living, medical and nursing conditions of a small group of disabled persons, selected on the basis of disability types, gender and age, to ask them more specific questions about their status and expectations, to appreciate their physical and psychological capabilities, in order to better assess the types of services to be provided in the future Handimachal Centre.

This mission was carried out during three days in August 2007 by a team composed of three French volunteers (one occupational therapist and one physiotherapist, plus one member of MdH) and two members of HPVHA Shimla, with the involvement of local social workers who helped identifying locations.

Findings resulting from this mission confirm most of analysis resulting from the Disability Survey and give an interesting and practical vision on the status of disabled persons living in rural and urban areas of Kullu block.

The present document gives a summary analysis of the situations faced by the disabled persons met during the survey together with subsequent recommendations and suggestions for the Handimachal Centre.

### (1) THE PEOPLE

First and above all, we would like to express our gratitude to the following people, who accepted to meet us and share with us their stories, experiences, difficulties and hopes for the future:



Gautham and his school friends

**Gautham**, 21 years old

**Disability type:** physical; cannot walk

**History / Cause of disability declared:** at the age of 1.5 year, one day he had fever and an injection was made on each of his legs, then both legs became paralysed (we could not meet his parents to get their explanations)

**Diagnosis given by volunteers:** most probably polio

**Disability level as shown on certificate:** (not seen)

**Medical treatment:** none

**Autonomy level:** very high. His parents have rented a room near his school so that he can be independent and autonomous; his mother visits him every 3-4 days; gets help from his friends and neighbours; can manage alone for almost all activities; moves about on his hands or on his tricycle (provided by Welfare Office), sometimes with the help of his friends when terrain is uneven or for driving up or down slopes

**Education:** currently studying in 10<sup>th</sup> class

**Social and financial status:** lives alone for better autonomy; family is financially sound

**Private expectations:** wants to learn computers and is not rejecting the idea of marriage (after he has found a job)

**Recommendations by volunteers:** to go on his integration, this is a very nice example of strong will for autonomy and social integration; physical rehabilitation would have been required earlier, before muscle atrophy (which cannot be solved now after so many years).



Karan, isolated from the world

**Karan**, 22 years old

**Disability type:** Multiple disability (cannot move at all and express himself, only eyes are moving; global movements are uncontrolled)

**History / Cause of disability declared:** accident during delivery (doctor is suspected to have dropped the baby when handing it over to the midwife)

**Diagnosis given by volunteers:** probably cranial traumatism

**Disability level as shown on certificate:** 100%

**Medical treatment:** -

**Autonomy level:** none

**Education:** none

**Social and financial status:** younger brother is totally "normal" and good in study (out of home); mother is giving exceptionally good nursing care and showing great dedication to her son, but she does not dare to take her son outside because she is afraid that other people will be shocked or afraid.

**Private expectations:** Karen's mother is expecting to be able to take care of her son as long as possible

**Recommendations by volunteers:** (1) to find a wheel-chair and synthetic shell to sit Karan up right and stimulate his visual capacity; (2) to find a social helper to support the mother and release her, from time to time, from her daily duties so that she may also lead a "normal" social life.



Sonnu (Ajay Kumar)

**Sonnu**, 21 years old

**Disability type:** Physical: cannot walk, motor functions are limited by uncontrolled movements and stiff muscles

**History / Cause of disability declared:** "Had fever at the age of 20 days; doctor said it was a problem with the nerve in the neck"

**Diagnosis given by volunteers:** physical disability due to damage of brain during delivery (cerebral palsy)

**Disability level as shown on certificate:** (mother could not find it)

**Medical treatment:** none

**Autonomy level:** limited in movement but strong will power and intelligent boy; can express himself (although he cannot articulate words properly), has a very good understanding

**Education:** none but his mother thinks that he could learn reading easily

**Social and financial status:** very modest family, Sonnu lives with his parents, has 3 brothers and 1 sister; he has many friends in the neighbourhood and a good social life

**Private expectations:** would like to work (in a shop or in an office)

**Recommendations by volunteers:** to learn reading (even with his brothers or friends) and later exercise him to use a figurative keyboard to express his wishes more easily.



Tsering Namgial and his mother

**Tsering Namgial**, 15 years old

**Disability type:** Multiple handicap

Muscle dystrophy, cannot stand up, uncontrolled movements, can grab small things (pen, toffee) in his hands with great difficulty and without accuracy; mentally impaired, cannot talk distinctly

**History / Cause of disability declared:** mother does not know

**Diagnosis given by volunteers:** cerebral palsy

**Disability level as shown on certificate:** no certificate

**Medical treatment:** parents spent lot of money on medicines, without success

**Autonomy level:** weak

**Education:** none

**Social and financial status:** Tibetan refugees family, condition is poor; mother is taking good care of her son and she shows great understanding and nursing capabilities; child can move on his knees to play with his friends, is very sensitive and expresses his emotions noisily. Also communicates with his mother by rough sign language

**Private expectations:** not expressed

**Recommendations by volunteers:** to sit the child in a wheel chair with synthetic shell and teach the essential gestures to his mother to delay stiffening of muscles and joint capsules (when possible).





Mira sharing her hopes with Thomas, French physiotherapist



**Mira**, 27 years old

**Disability type:** Physical (cannot walk, uses a wheel chair outside and a walker frame inside the house, cannot carry heavy loads)

**History / Cause of disability declared:** When she was 11, she felt a very strong pain on each side of her belly. She was given ½ tablet of a medicine (Bralgan) and the following morning she could not walk anymore

**Diagnosis given by volunteers:** most probably Spina Bifida with atrophy of spinal cord, leading to scoliosis and paralysis of legs

**Disability level as shown on certificate:** (not shown)

**Medical treatment:** did some physical rehabilitation exercises with a physiotherapist and recovered some strength in her right leg, but she found it hard to do and stopped. Parents took her to Chandigarh to consult a specialist (IRM examination taken, report states "Myelid Dorsal Spinal Cord Atrophy")

**Autonomy level:** high

**Education:** graduate (private school)

**Social and financial status:** lives with her parents, has 1 brother and 1 sister; financial status of family is good; Mira works as tailor in her own shop; she has many friends and likes to go out with them; contact is very good, very independent young woman

**Private expectations:** would like to get married; she is going to open another shop and has a proposal to teach tailoring (government job)

**Recommendations by volunteers:** to continue on the way of autonomy; to do specific exercises again in order to strengthen her body structure



Balak Ram



**Balak Ram**, 55 years old

**Disability type:** Physical (left arm is shorter and hand is not developed, main handicap appears for bimanual activities)

**History / Cause of disability declared:** accident when he was a baby (7 months): his left arm was burnt and never developed

**Diagnosis given by volunteers:** atrophy of the hand

**Disability level as shown on certificate:** not shown

**Medical treatment:** no operation possibility at that time, was healed by a local doctor with macerated herbs and "cured" within 6 months

**Autonomy level:** high

**Education:** 4<sup>th</sup> only (was raised by his grand-mother as his mother was dumb)

**Social and financial status:** Balak Ram is married and has 3 sons. After leaving school he worked in the fields, then during 12 years in a sawmill; nowadays works as a painter; did not ask for a government job due to his low level of education

**Private expectations:** not expressed

**Recommendations by volunteers:** stay on the way to autonomy.



Dolma



**Dolma**, 62 years old

**Disability type:** Physical (cannot walk properly)

**History / Cause of disability declared:** does not know

**Diagnosis given by volunteers:** club-foot

**Disability level as shown on certificate:** no certificate

**Medical treatment:** was operated at the age of 18-19 in Mussorie but situation got worse

**Autonomy level:** good

**Education:** until 4<sup>th</sup>, stopped due to financial problems

**Social and financial status:** lives with her son in the Tibetan refugee settlement of Kullu, is dependant on her son

**Private expectations:** wants to stay with her son and does not want to get operated

**Recommendations by volunteers:** use a walking stick to relieve other leg while walking



Premi Devi and her husband

**Premi Devi**, 50 years old

**Disability type:** physical (paralysis on right side of the body: cannot walk properly nor use right arm, swallows food with difficulty)  
**History / Cause of disability declared:** stroke in 2004  
**Diagnosis given by volunteers:** CVA (cerebro vascular accident) not followed by proper physical rehabilitation  
**Disability level as shown on certificate:** no certificate  
**Medical treatment:** was not proposed proper treatment in hospital (only glucose), consulted a local ayurvedic doctor  
**Autonomy level:** not good, feels dependant on every body for all activities  
**Education:** none  
**Social and financial status:** very modest family, lives with her husband  
**Private expectations:** is willing to learn a more adequate walking technique in order to walk easily (with stick)  
**Recommendations by volunteers:** physical rehabilitation would have been vital for Premi Devi after her stroke; in spite of her age, she could still do some physical exercises to improve her walking and moving range, together with a specific training to improve her abilities in every day life (to dress alone, cook, etc.)



Santosh

**Santosh**, 40 years old

**Disability type:** Mental (from birth)  
 Does not do anything, has no will power, very often gets angry and becomes violent, escapes from home from time to time  
**History / Cause of disability declared:** "is like this since birth, until 10-11 years old she did not grow up properly"  
**Diagnosis given by volunteers:** mental impairment, should be further explored with adequate resources  
**Disability level as shown on certificate:** no certificate ("doctor said everything was normal, because she could tell her name and age")  
**Medical treatment:** takes tablets every day: Medica (trihexy phenidyl) and Peradyl ; "otherwise she becomes violent"  
**Autonomy level:** none (was not able to answer the questions, her sister-in-law did not let her express herself)  
**Education:** went a few days to school but was violent  
**Social and financial status:** lives with her mother, brother and sister-in-law (who did the interview); she enjoys talking to her mother  
**Private expectations:** not expressed by Santosh but the family wants to take care of her as long as necessary  
**Recommendations by volunteers:** to take her to psychiatric hospital in Shimla for evaluation, checking of chemical treatment and issue of disability certificate. Specific occupational therapy workshops can be organised in the future Handimachal Centre to develop mental and manual capabilities of such persons.

And also...

**Lata Devi**, 20 years old

**Disability type:** Physical (cannot walk properly, especially on long distances)  
**History / Cause of disability declared:** Post polio residual (same)  
**Diagnosis given by volunteers:** 65% - "post polio residual / palsy on lower limbs with placid ankle joint and shortening"  
**Disability level as shown on certificate:**  
**Medical treatment:** none  
**Autonomy level:** high  
**Education:** College  
**Social and financial status:** Lata lives with relatives because of studies; she is aware of quota possibilities; she has lots of friends and does not feel shy mixing with other people  
**Private expectations:** Priority is to find a job, preferably in office or in teaching  
**Recommendations by volunteers:** To wear orthopaedic shoes and/or orthosis in order to compensate body structure disbalance (go to government hospital to ask for help)

**Shalini**, 22 years old

**Disability type:** Multiple handicap (visual and mental)  
**History / Cause of disability declared:** Shalini was born premature (7 months) and wears spectacles since the age of 7; has heavy headaches;  
**Diagnosis given by volunteers:** Mental impairment seems more important than visual one; father does not seem to accept mental weakness of her daughter  
 40% for low vision (no mention of mental disability)

Disability level as shown on certificate:	various medicines
Medical treatment:	Medium: can do house work but has no will for anything; father is doing interview and does not allow her daughter to talk, she seems over-protected by family
Autonomy level:	Stopped her studies (+2) because she was too slow
Education:	Well-off family, 4 other children
Social and financial status:	Not expressed, does not know
Private expectations:	Mental impairment should be properly assessed and autonomy development should be proposed by way of specific occupational therapy workshops
Recommendations by volunteers:	
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<b>Boby, 34 years old</b>	
Disability type:	Mental (Downe Syndrome) + allergy on eyes, teeth are falling, skin is too dry ("she uses too much soap")
History / Cause of disability declared:	"Mental illness"
Diagnosis given by volunteers:	Downe Syndrome
Disability level as shown on certificate:	60%
Medical treatment:	none
Autonomy level:	weak
Education:	went to school when 5-6 years old but was disturbed by other children and ran away
Social and financial status:	Lives with her mother (widow) and 2 brothers; very poor family; has not been receiving her pension (200 Rs) for 6 months (problem with new postman and penchayat); ID card delivered by Welfare office is not recognised by bus drivers
Private expectations:	None
Recommendations by volunteers:	To go back to Welfare Office for validation of ID card and complain about non payment of pension. Once the Handimachal Centre is opened, propose to join occupational therapy workshops
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<b>Loser, 7 years old</b>	
Disability type:	Mental
History / Cause of disability declared:	Child has no conscience of danger, cannot stay in one place, has very unpredictable reactions (violent), talks very slowly
Diagnosis given by volunteers:	Do not know, "mental illness"
Disability level as shown on certificate:	Behaviour problem, similar to hyper activity (to be properly assessed with appropriate techniques)
Medical treatment:	No certificate
Autonomy level:	None
Education:	Good but disorderly behaviour
Social and financial status:	None
Private expectations:	Lives with his mother (also mentally retarded according to neighbours) and 6 other children, in the Tibetan settlement, family is very poor
Recommendations by volunteers:	None
Recommendations by volunteers:	This child should be examined by psychologists and, depending on results, attend a specialised school for mentally impaired children (in Kullu NAV Chetnav for example)
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<b>Gohari Devi, 37 years old</b>	
Disability type:	Deaf and dumb
History / Cause of disability declared:	By birth
Diagnosis given by volunteers:	Deaf and dumb
Disability level as shown on certificate:	100%
Medical treatment:	never went to see a doctor
Autonomy level:	Good (very dynamic and good will power)
Education:	None
Social and financial status:	Gohari Devi lives with her husband (also disabled: he can hear a little and talk with stammering) who is a labourer; they have a son (normal). She can watch TV and communicates by signs; she has a small job (weaving)
Private expectations:	
Recommendations by volunteers:	To continue on the way of integration and have her hearing capabilities checked up, because she can hear strong sounds
<hr/>	
<b>Mast Ram, 45 years old</b>	
Disability type:	Physical (amputation of left leg, above the ankle)
History / Cause of disability declared:	Accident (was hit by a bus)
Diagnosis given by volunteers:	Same
Disability level as shown on certificate:	50%
Medical treatment:	was operated in Kullu; received money from the government to have a prosthesis made but the money did not reach him

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Autonomy level:	(penchayat members are suspected) Good, walks with two simple bamboo sticks but can only work in sitting position
Education:	None
Social and financial status:	Lives with his wife and works (breaks stones, same job as before accident)
Private expectations:	To walk more easily
Recommendations by volunteers:	To have a prosthesis done and walk with crutches (he was advised to go to the Red Cross mela in Kullu the following day)

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### Amit, 28 years old

Disability type:	Physical, cannot walk properly
History / Cause of disability declared:	Polio since the age of 2 (no polio injection)
Diagnosis given by volunteers:	Polio
Disability level as shown on certificate:	45%
Medical treatment:	used to wear orthopaedic shoe but did not find it "nice"
Autonomy level:	Excellent
Education:	10+2
Social and financial status:	Amit is married with child (8 months); lives in the family house and is managing his parents' shop; family is economically sound
Private expectations:	Wants to invest on the stock exchange
Recommendations by volunteers:	To wear again orthopaedic shoe in order to slow down structural disequilibrium in older age

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## (2) A VERY POSITIVE BACKGROUND FOR COMMUNITY INTEGRATION...

As anticipated before the survey, considering the social structure of village life in Kullu district, the most positive point confirmed by the visits to disabled people's homes is the **strong solidarity and sympathy** which is underlying their close environment.

Disabled children and adults **do not seem to be rejected or unconsidered** by relatives or neighbours, even though they sometimes represent a heavy load in every day life for the family: all persons met were clean, well fed and in good health (if not considering the impact of their impairment). The **same loving care** to children which is characteristic of Indian families is also prevalent in favour of disabled children. Whenever their physical condition allows it, **disabled children or adults are not isolated** from the rest of the population. This was really obvious when we met [Gautham](#), [Sonnu](#), [Mira](#), [Lata](#), and even [Boby](#) or [Loser](#). Only once during our visit did we meet one disabled person totally kept isolated from the world outside his house ([Karan](#), 22 years old) and her mother explained that she was afraid of other people's reactions as her son was suffering such severe handicap.

But the extreme case of [Karan](#) and his mother also revealed how deep and genuine the **dedication** of a mother can be for her disabled child and how **common practical good sense** can create **exceptional nursing capabilities** within the families: although this young man (hardly a boy, if judging at first sight) has been lying in his bed for 22 years, without the possibility of moving himself and hardly able of turning his head, and without any mean of expressing his most vital wishes, his body is always kept clean and is not affected by bed sores. His mother has organised a small bathroom in the room next to his, where she gives him bath every afternoon before making him sit in an armchair for 2 or 3 hours nearby the window.

Some disabled persons show a **very positive attitude in life** and, depending on their physical capabilities and their level of personal **autonomy** (= ability to express their wishes, mental and moral ability to decide for themselves and project their life in the future), are already **integrated in the economical environment by way of studies or jobs**. For example, [Amit](#) is running his own shop and has created a family, [Mira](#) is contemplating to open a second tailor shop, [Gautham](#) lives independently in order to finish his studies, [Lata Devi](#)'s priority is to finish her studies and find a job, [Balak Ram](#) has been working all his life and has three sons in spite of his handicap...

Many disabled persons met during the survey hold a medical certificate stating their percentage of disability and receive a pension of 200 Rs / month, which shows a **certain level of social awareness** even if medical understanding is not good. Some of them are also aware of the possibility of getting reserved government jobs, although none of them has been able to apply.

Our observation mission allowed us to come across some **interesting initiatives** in the field of disability, for example the Nev Chetna school in Kullu, which provides education to around 20 mentally impaired children and which employs two young occupational therapists trained in a government institution in Sundernagar. Kullu town also hosts a private school for blind children which is doing tremendous work in the field of community integration.

### **(3) ... WEAKENED BY STRUCTURAL LIMITATIONS**

One of the most striking aspect of this observation mission was of course the confirmation that many disabled persons (or their families) **lack information about the nature of their impairment, their origin and possible solutions.**

This **misinformation** is revealed when personal histories are being told:

- ü injections or medicines which result in paralysis of legs (for **Gautham** and **Mira**), the “nerve” is damaged (**Karan** and **Sonnu**), **Tsering Namgial**'s mother who has no idea of what could have happened to her son: the **lack of medical knowledge** is there of course, more obviously when education is poor, but it also means that **many doctors did not play their information role** (and were probably not able to do it);
- ü **the right actions have not been taken** upon appearance of disability symptoms: **Premi Devi** did not go to hospital after her stroke three years ago and could not recover the use of her right members, young hyper active **Loser** was never shown to a doctor or to a psychologist, **Gohari Devi** never went to see a doctor to have her hearing capacities checked;
- ü **the response of medical professionals could not match the need of some disabled persons:** **Shalini** has been declared as 40% impaired for low vision but her mental impairment has not been assessed and is not recognised (and does not exist for her father), **Dolma** was operated in Mussorie “but situation got worse”, **Tsering Namgial**'s parents “spent lot of money on medicines, without success” when it is obvious that only physical rehabilitation will improve his situation, etc.

Apart from the financial needs of past and present medical institutions, either private or public, the **poor financial situation of most families** is also an important factor for the increase of handicap: **Premi Devi** complained that only glucose was given to her in hospital but this might be because the family did not have enough money to cover the expenses of a more efficient chemical treatment; young **Lata** was not proposed to wear any orthopaedic shoe but was the family ready to cover that expense? On the contrary, **Mira**'s parents are reasonably well-off and took her to many doctors, including to a specialised hospital in Chandigarh last year, where she could undergo an expensive MRI analysis and a precise diagnosis was given to her (nevertheless, they asked us to reconfirm the meaning of the diagnosis).

**In the field of education, a lot remains to be done to integrate disabled children or young persons,** whose impairment seems to isolate them totally from a form of knowledge and personal realisation: **Sonnu**, in spite of his deformity, has a strong desire to open his mind to the outside world but nobody tried to teach him reading; **Tsering Namgial**, **Loser** and **Shalini** **need special educational guidance** to stimulate and structure their intellect and build their future both in autonomy and integration.

Most of the persons interviewed during the Disability Survey in January-February and, to a lesser extent, during our observation mission (as this mission was realised mostly in an urban area), seem **isolated and left alone to cope with their handicap**, which is *de facto* increased: none of them declared that they have found the right help or that they are trusting such or such specialist to improve their life. This reveals the flagrant **lack of rehabilitation structures** (including at home), **orthopaedic services** and, for mentally impaired persons, of a **special skill centre** (“sheltered workshop”).

As far as **work** is concerned, none of the persons we met had the possibility or capability of applying for a reserved job in a government institution or private company, which shows that there might be a **lack of information, advocacy or guidance** in this respect. Nevertheless, such persons are quite capable of autonomy in work and some of them are self-employed and even run their own business (Amit, Mira), which can be very demanding.

In two cases, **difficulties in receiving pensions or special benefits were reported**: **Boby**’s mother did not receive her daughter’s pension for 6 months and she is attributing this to the new postman of the village who might not know her or simply kept the money for himself; when she went to complain to the post office, she was told that the computer was not working and that they could not check and the penchayat pradhan is not helping her in this matter; she is also facing difficulty because her daughter’s ID card issued by the Department of Social and Women’s Welfare office is not recognised for free transportation – but she has not gone to the Welfare office to find out a solution. Similarly, **Mast Ram** (45) is complaining that he did not receive the funds that were allocated to him to have a prosthesis done, and he is blaming the penchayat for this. Whether such accusations are justified or not, the fact is that disabled people are not completely confident in social institutions to ensure the full satisfaction of their rights as far as disability is concerned.

#### **(4) WHAT COULD BE THE RESPONSES BROUGHT BY THE FUTURE HANDIMACHAL CENTRE**

First of all, the Handimachal Centre could act as an **integrated information cell**, where disabled persons and their families could find responses concerning the social and legal aspects of their status: advice to find the appropriate medical or rehabilitation structure (if not provided by the centre), help to fill up forms and place complains, etc. A **link between all existing structures** would thus be created, allowing disabled persons to benefit of all solutions present in Himachal Pradesh and giving them advice in this respect, so that they do not feel isolated anymore.

The Handimachal Centre, offering the possibility of meeting interesting and efficient specialists, together with the Handimachal Training School, providing training for disability professionals (from other parts of India or from abroad), would allow the appearance of a **disability reference centre in Himachal** for families and generally all persons interested to reduce the handicaps faced by disabled persons in society.

In order to give this pilot initiative its full dimension and provide the best services, the chore staff of the Handimachal Centre should comprise:

- Ü one **secretary/medical assistant** (for the management of the information cell and database, reception and help to the visitors),
- Ü one **resident doctor** (2-3 days a week), who has received adequate training in the field of disability,
- Ü one **physiotherapist** (for physical rehabilitation) and one **occupational therapist** (more involved with the development of mentally impaired persons), **each one acting in the centre but also within the disabled persons’ homes** (1 or 2 days a week) in order to help disabled persons with physical exercises and give them advice in terms of hygiene and practical adaptation of their environment.

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