Assessing Community Health needs of the disabled in Nindura Block and exploring the existing Health Service Gaps in the Health system.

A Study conducted for SPARC-India in Nindura Block of Uttar Pradesh

-By Dr.Gitesh H Shelar & Dr. Sushil Patil

TISS -MHA 2010-12

INTERNSHIP ASSIGNMENT FOR SPARC-INDIA

Assessing Community Health needs of the disabled in Nindura Block and exploring the existing Health Service Gaps in the Health system.

World Health Organisation's definition of health:

> ***'To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is positive concept emphasising social and personal resources, as well as physical capacities.' (WHO, 1998)***

However the health of the individual is determined by a broad range of factors which includes the availability to health services, access to these facilities, various barriers for availing these services, personal factors and genetic makeup of the individual.

In recent times there has been lot of impetus placed on the development of health status as the former is considered to be the most critical measure for evaluating the country's development progress. With most of the evaluation methods focusing on the health status of the population suddenly the health system has came into limelight and is being evaluated for its effectiveness in providing good quality of health services. The reason for placing importance in the health status of the population is the approach that most of the international bodies have towards health. As per the economist views every country must invest in health as it results in healthier workforce which could yield better production rate .Such type of approach imbibes the capitalist theory while completely ignoring the idea of welfare state. Now the problem with such approach is clearly delineated by most of the academician and has been the topic of debate during international conferences on health.

The problems with capitalist view are as follows:-

- The state may invest in health as a mean to achieve higher production ultimately leading to the end of higher economic growth. The problem lies in the approach itself as the state may concentrate only on those who contribute to the workforce while undermining the health needs of Aged, ill, children and specially disabled.
- Also the state may place less importance to health need of women and children as comparatively they contribute less to the economic growth of the country.

- In addition to it the country may have agricultural economy with majority of the workforce being active only for a limited period of the year.

Due to such issues there has been lot of debate about the approach that the state should have towards the health of the population.

A lot of academician and health researchers have endorsed the idea of Welfare State where the state is responsible for protecting the health of the population by providing them with good quality of services free of cost. However with the new health sector reforms instilled in the health system the idea of user fees came into play thereby raising issues about the accessibility and equity in the existing healthcare systems around the world.

With so much of history backing up the required approaches in the health care system most of the international bodies have now endorsed the view of "Health as a Right". Such view entails the right of every individual to have highest attainable health. But how far the countries have been successful in securing this right of its citizen is questionable. It is observed in most of the developing countries the health system has been apathetic towards the plight of the marginalized groups and specially the disabled. To address this issues a lot of conventions and acts have been formed to protect the right of this vulnerable groups. These conventions are aptly supported by various researches and paper published by renowned scientist working in the field of health as right.

Here we are concentrating the on realization of the disabled people's right to health. While reviewing the international literature available on the right to health for the disabled the following themes come up:-

- Health, social care and rehabilitation are provided in and for non-disabled environments. Programmes are often ongoing with few clearly focussed and community based goals.
- Support services are often controlled and allocated by health service professionals and with limited participation of disabled service users.
- Health personnel lack expertise in the provision of general health care for people with disabilities, health information and health advice is often limited and negative assumptions abound.
- Medical services are orientated towards prevention and acute treatments rather than long-term supports, particularly for mental health system users.
- Medical services do not empower people to live independently in the community.
- Services are poorly coordinated and integrated and this has a major impact on the planning of quality health and social care services.
- The shift to a social model of disability has been hindered by a historical and institutional reliance on a medical and welfare model of disability.

However, there have been some very positive developments in the provision of health services for people with disabilities, notably:

- The provision of services by people with disabilities for people with disabilities,
- The representation of people with disabilities on decision-making bodies and the involvement of disability service users in the planning, organisation and monitoring of services.
- The growth of more targeted health services for people with disabilities with a greater emphasis on the coordination of services and the development of multi-disciplinary teams.

In contrast to the medical model of disability, the social model of disability has been the basis upon which people with disabilities have promoted disabled people's autonomy and control in their own lives and as a civil rights issue.

As Vic Finkelstein argued in 1980:

Once social barriers to the re-integration of people with physical impairments are removed, the disability itself is eliminated. The requirements are for changes in society, material changes to the environment, changes in environmental control systems, changes in social roles, and changes in attitudes to people in the community as a whole. The focus is decisively shifted on the source of the problem – the society in which disability is created.

The changing perceptions and attitudes to people with disabilities has resulted in a shifting policy focus on inclusion rather than exclusion, on rights rather than charity and on independence rather than dependence, independent living rather than institutionalised living. This has resulted in a rejection by people with disabilities of policies that promote care and management. Many service developments are aspiring to good practice located in community-based interdisciplinary approaches with the maximum participation of disabled person and his/her family in decision-making. The social model of disability has stressed the need for attitudinal changes and on the basis that it is attitudes that disable more than the disability itself.

I. Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (adopted by the UN General Assembly in 1993).

A significant outcome of the Decade of Disabled Persons was the adoption, by the UN General Assembly, of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1994. Although not legally binding, the Standard Rules represent a strong moral and political commitment by Governments to take action for the equalization of opportunities for people with disabilities. The rules serve as an instrument for policy-making and as a basis for technical and economic cooperation. The Standard Rules consists of 22

rules summarizing the message of the UN. The 22 rules cover four chapters - preconditions for equal participation, target areas for equal participation, implementation measures, and the monitoring mechanism - and cover all aspects of life of disabled persons.

The measures for international good practice can be found in legal and other measures established by the United Nations and the World Health Organization that are shaping the development of international policies around the world.

II. United Nations :-

Disability is now part of the mainstream international human rights agenda the emergence of which was marked by the 1975 UN General Assembly Declaration on the Rights of Disabled Persons. This was followed by International Year of Disabled Persons in 1981 and the development of a World Programme of Action. In 1985 the Universal Declaration of Human Rights was extended to include disabled people.

In 1993 the UN Rules on the Equalization of Opportunities for Disabled Persons addressed participation in eight specific areas: accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion.

Similarly the UN reinforced the importance of social model of disability in 1994 which states that ***"...society creates a handicap when it fails to accommodate the diversity of all its members" and "People with disability often encounter attitudinal and environmental barriers that prevent their full, equal and active participation in society".***

The main instruments of the United Nations are:

- Universal Declaration of Human Rights (1948), covering fundamental political and civil rights, contains fundamental human rights such as the right to life, liberty and free speech.
- International Covenant on Civil and Political Rights, 1966, which came into force in 1976, upholds the rights set out in the Universal Declaration concerning the right to life, liberty, equality before the courts, peaceful assembly, marriage and having a family, freedom of association, conscience, thought and religion. Article 26 guarantees equality of treatment without unfair discrimination, including discrimination on the basis of disability. Various articles are relevant to people with disabilities in the broad area of health, residential and social care, including inhumane or degrading treatment and consent to medical or scientific treatment (Article 7), institutional abuse (Article 9), privacy (Article 17), the right to marry and found a family (Article 23) and equality in access to public affairs, voting and public services (Article 25) (Quinn, 1995).

The first four Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, concern the provision of awareness raising, medical care, rehabilitation and support services.

III. World Health Organisation

The World Health Organisation, established as the health arm of the UN in 1948, has the objective of the attainment by all peoples of the highest possible level of health. Health is defined in WHO's Constitution as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

The rights of people with disabilities to have the same opportunities as others in their communities and societies are now well recognized. Despite the increased awareness about the community participation of people with disabilities and the developing policies and legislation related to disability, there are still many disabled people who do not have adequate opportunities to access rehabilitation services to attend school, to achieve income producing work, or to participate in activities characteristic of their communities.

The WHO has also established a classification for the functioning, health and disability of people. The ICF (International Classification of Functioning, Disability and Health) was established in order to focus attention on quality of life, health and social policies to improve access and treatment, and take account of social aspects of disability by focussing on the impact of the social and physical environment on a person's functioning.

According to the WHO, "Health and rehabilitation can no longer be understood solely in terms of orthodox medical interventions and conventional notions of 'care'. These centre almost exclusively on the perceived limitations of individuals rather than on society's failure to accommodate the needs of people with disabilities. Thus, there is an urgent need for an approach that cares not only about disabled people but also about society and its structures" (WHO, 2001:1c) Recommendations made by the WHO include:

- ***A holistic approach:*** access, legislation and funding. This includes the development of community-based services, accessible services, anti-discrimination laws, and support.
- M***edical services.*** This includes the provision of high quality medical services as a basic human right, participation of disabled people in allocation of resources, fully accessible services in both mainstream and targeted services, recruitment and training of disabled people as doctors, nurses and other medical service personnel.
- ***Rehabilitation services.*** This includes the removal of barriers to full participation and where necessary appropriate education, training and skills to secure meaningful participation in economic, social and cultural life of the community.

- ***Support services.*** Access to support services should be a basic human right and that provision should be free, participation of disabled people and their families and disabled representatives of disability organizations should be a key feature and programmes should be community based and controlled by people with disabilities.
- ***Awareness-raising.*** Awareness-raising targeted to all sections of the community with the participation and involvement of disabled people.

In evaluating the UN Standard Rules on medical care, rehabilitation, support services and personnel training the WHO has provided a number of good practice examples that are helpful to service developments and the commissioning of services. These include:

Medical care

- The provision of programmes of early detection, diagnosis, assessment and treatment,
- Full involvement of people with disabilities and their families in the planning and monitoring of services and programmes.
- Provision of medical care for children and adults with disabilities in the general medical system.
- Awareness raising for health and medical personnel.
- Provision of disability programmes in multi-disciplinary teams of professionals and the full participation of people with disabilities and their families in the planning and evaluation of these programmes.
- Free provision of medical care for people with disabilities.
- Trained medical and paramedical staff who are equipped to provide medical care to people with disabilities.
- Primary health care model.
- Provision of information and communications about services in Braille/tape, sign language, easy readers etc.

Rehabilitation

- Provision of rehabilitation services to enable all people with disabilities, including people with severe or multiple disabilities to reach their optimum level of independence and functioning.
- Local community based provision of rehabilitation services.
- Involvement of people with disabilities and their families in the design, organization, provision and evaluation of rehabilitation programmes.

Support services

- Access to assistive devices, provided free of charge or affordable.
- Development, production, distribution and servicing of equipment and dissemination of information about them should be undertaken by the State.
- Provision of personal assistance, interpreter services and equipment by the State in order to achieve equalisation of opportunities.
- Community based and home based support.
- Financial support to carers and to families with children with disabilities.
- Involvement of people with disabilities and their families in the planning, organisation, provision and monitoring of support services.

Personnel Training

- Human resource planning to ensure the optimum mix of health professionals in order to provide the best quality service.
- Disability awareness training for health personnel.
- Training programmes should stress the importance of the principle of the full participation and equality for people with disabilities.
- Training programmes to be developed in consultation with people with disabilities and people with disabilities should be involved as teachers, instructors and advisors in staff training programmes.

The above conventions provide entitlements to the disabled which includes right to health providing equal opportunity for the disabled people to enjoy highest attainable level of health. The right to health includes the right to timely and appropriate health care, the underlying determinants of health, as well as participation of the population in all health related decision making at various levels.

This also includes availability, accessibility, acceptability and quality of health care and other related goods and services. Under, quality it states that "As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality". Under accessibility it states that health facilities, goods and services have to be accessible to everyone without discrimination. This covers:

Non-discrimination so that health facilities, goods and services are accessible to all, particularly the most vulnerable and marginalized people

Physical accessibility whereby health facilities, goods and services are within safe physical reach for all sections of the population, especially vulnerable or marginalized groups. Accessibility further includes adequate access to buildings for persons with disabilities.

Economic accessibility (affordability) whereby health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the

underlying determinants of health, has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.

Information accessibility, which includes the right to seek, receive and impart information and ideas concerning health issues. This should include the right to have personal health data treated with confidentiality.

In the area of Acceptability, health facilities, goods and services must be **culturally appropriate**, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned. The requirement to promote the right to health requires States, to ensure that "health services are culturally appropriate and that health care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups". Similarly, this requires that ***"medical practitioners and other health professionals meet appropriate standards of education, skill and*** and that "there is provision of "appropriate training for health personnel, including education on health and human rights". Regarding the provision and funding for health services ***"States have to ensure the appropriate training of doctors and other medical personnel, the provision of a sufficient number of hospitals, clinics and other health-related facilities, and the promotion and support of the establishment of institutions providing counselling and mental health services, with due regard to equitable distribution throughout the country".***

Article 12.2 (d) covers the right to health facilities, goods and services including

- ***Provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education;***
- ***Regular screening programmes;***
- ***Appropriate treatment of prevalent diseases, illnesses, injuries and disabilities, preferably at community level;***
- ***Provision of essential drugs;***
- ***Appropriate mental health treatment and care.***

IV. UNCRPD

UNCRPD is an international convention which protects the rights of the disabled. It provides the person with disability with the same human rights which are enjoyed by the others. It defines disability in terms of Social model of disability.

Preamble of Convention states:

'Disability is an **evolving** concept, and that disability results from the **interaction** between persons with impairments and attitudinal and environmental barriers that hinders full and effective participation in society on an equal basis with others'

As per the above definition there is radical shift in the perception and understanding of disability. A shift from medical perspective to human rights based approach.

According to the convention Persons with disabilities are not to be viewed as "objects" of charity, medical treatment and social protection; rather as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

The Convention protects the following Rights of the Disabled.

- ✓ Equality before the law without discrimination (article 5)
- ✓ Right to life, liberty and security of the person (articles 10 & 14)
- ✓ Equal recognition before the law and legal capacity (article 12)
- ✓ Freedom from torture (article 15)
- ✓ Freedom from exploitation, violence and abuse (article 16)
- ✓ Right to respect physical and mental integrity (article 17)
- ✓ Freedom of movement and nationality (article 18)
- ✓ Right to live in the community (article 19)
- ✓ Freedom of expression and opinion (article 21)
- ✓ Respect for privacy (article 22)
- ✓ Respect for home and the family (article 23)
- ✓ Right to education (article 24)
- ✓ Right to health (article 25)
- ✓ Right to work (article 27)
- ✓ Right to adequate standard of living (article 28)
- ✓ Right to participate in political and public life (article 29)
- ✓ Right to participation in cultural life (article 30)

As we are attempting to assess the Health needs of the disabled, the focus will be primarily on the Article 25 which provides the disabled with Right to Health.

Article 25 - Health

Article 25 recognizes that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. It compels States Parties to take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

As per Article 25 of UNCRPD, all the signatory States Parties shall:

a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;

c) Provide these health services as close as possible to people's own communities, including in rural areas;

d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;

e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

The convention also provides for ***Conference of the State Parties*** to consider any matter with regard to the implementation of the convention. It also proposes for the formation of the "***Committee on the Rights of the Person with Disability***", which include a body of independent experts tasked with reviewing the states implementation of the convention.

As per the convention all activities involved regarding the implementation of UNCRPD must include the participation of persons with disabilities, which entails the motto of

'Nothing about us without us'

V. THE PERSONS WITH DISABILITIES ACT, 1995

The Persons with Disabilities Act, 1995 (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. This is an act to give effect to the proclamation and equality of the people with disability in the Asian & Pacific region.

As per PWD Act 1995 Disability means-
a) Blindness
b) Low vision
c) Leprosy cured
d) Hearing impairment
e) Locomotor disability

f) Mental Retardation
g) Mental illness

Persons with Disability:- means a person suffering from not less than 40% of any disability as certified by a Medical Authority. Under PWD Act 1995, the disabilities mentioned above have been included in order to enable the persons suffering from disabilities to derive certain benefits/ concessions provided by the State Govt./ U.T. Administration/ Central Ministries/ Department and Local Authorities.

IMPLEMENTATION OF PERSONS WITH DISABILITIES ACT 1995 (Section 25 of PWD Act)

a) Survey of disabled
b) Promote various methods of preventing disability
c) Screen Children every year to identify at risk cases :-
d) Provide Facilities to Train PHC staff
e) Sponsor awareness campaign
f) Measure for mother and child care
g) Educate the Public through the Pre-schools, Schools, PHCs, Village
h) Level Workers and Anganwadi and Anganwadi workers
i) Create awareness amongst the masses through Television, Radio and other media

Current Situation of Disability in India

In most of the developed as well as developing countries the government bodies has always been ignorant about the increasing burden of Disability on the health status of the country. In developing country like India efforts for estimating the magnitude of problem of disability is lacking. Till date only three rounds of NSSO has attempted to estimate the prevalence of Disability in India out of which the 58th was the first one that included Mental retardation as a form of disability in their study.

Following are the highlights of the report published by NSSO following their 58th round during July-December 2002.

- About 8.4 per cent and 6.1 per cent of the total estimated households in rural and urban India respectively reported to have at least one disabled person. The average size of these households was estimated to be 5.7 in both the sectors, which was significantly higher than the average household size in general.
- The number of disabled persons in the country was estimated[1] to be 18.49 million during July to December, 2002. They formed about 1.8 per cent of the total population.
- About 10.63 per cent of the disabled persons suffered from more than one type of disabilities.
- For every 100000 people in India, there were 1755 who were either mentally or physically disabled. Among the rural residents, the prevalence of disability was 1.85 per cent and that among the urban, it was 1.50 per cent. The rate for males was 2.12

and 1.67 per cent while that for females was 1.56 and 1.31 per cent in rural and urban India, respectively.

- Among the different types of disabilities, the prevalence of locomotor disability was highest in the country – it was 1046 in the rural and 901 in the urban per 100000 persons. This was followed by visual disability and hearing disability.
- About 69 persons per 100,000 were either born disabled or become disabled for some reasons in India during the last 365 days. The incidence rate was also observed to be higher among males than that among females.
- About 84 per cent of the mentally retarded and 82 per cent of the persons having speech disability were born with disability. For persons with other types of disability, they acquired disability during the course of life and it is largely associated with the old age.
- About 13 per cent of the physically disabled were observed to be severely disabled as they could not take self-care even with aid/appliance.
- About 47 per cent of the disabled were never married. The situation is worst among the mentally retarded..
- About 55 per cent of the disabled in India were illiterate and about 9 per cent completed 'secondary and above' level of education.
- Out of 1000 disabled persons, only 15 to 35 completed any vocational course and of them, 74 to 80 per cent in non-engineering stream.
- The current enrolment ratio per 1000 disabled persons of age 5-18 years in the ordinary school was higher in the rural than in the urban – 475 and 444, respectively for the two sectors.
- About 11 per cent of disabled persons of age 5 - 18 years were enrolled in the special schools in the urban as compared to even less than 1 per cent in the rural.
- About 26 per cent of the disabled persons were employed. The proportion of employed among the mentally retarded was the lowest at 6 per cent.
- About 37 per cent of the disabled (age 5 +) as a whole were working before the onset of disability.
- The survey reveals that about 3 per cent of the disabled were living alone and 5 per cent lived with their spouse only.

Definition as per NSSO 58th Round:-

Disability: A person with restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being was treated as having disability. It excluded illness/injury of recent origin (morbidity) resulting into temporary loss of ability to see, hear, speak or move.

Mental disability: Persons who had difficulty in understanding routine instructions, who could not carry out their activities like others of similar age or exhibited behaviours like talking to self, laughing / crying, staring, violence, fear and suspicion without reason were considered as mentally disabled for the purpose of the survey. The "activities like others of similar age" included activities of communication (speech), self-care (cleaning of teeth,

wearing clothes, taking bath, taking food, personal hygiene, etc.), home living (doing some household chores) and social skills.

Visual disability: By visual disability, it was meant, loss or lack of ability to execute tasks requiring adequate visual acuity. For the survey, visually disabled included (a) those who did not have any light perception - both eyes taken together and (b) those who had light perception but could not correctly count fingers of hand (with spectacles/contact lenses if he/she used spectacles/contact lenses) from a distance of 3 metres (or 10 feet) in good day light with both eyes open. Night blindness was not considered as visual disability.

Hearing disability: This referred to persons' inability to hear properly. Hearing disability was judged taking into consideration the disability of the better ear. In other words, if one ear of a person was normal and the other ear had total hearing loss, then the person was judged as normal in hearing for the purpose of the survey. Hearing disability was judged without taking into consideration the use of hearing aids (i.e., the position for the person when hearing aid was not used). Persons with hearing disability might be having different de grees of disability, such as profound, severe or moderate. A person was treated as having 'profound' hearing disability if he/she could not hear at all or could only hear loud sounds, such as, thunder or understands only gestures. A person was treated as having 'severe' hearing disability if he/she could hear only shouted words or could hear only if the speaker was sitting in the front. A person was treated as having 'moderate' hearing disability if his/her disability was neither profound nor severe. Suc h a person would usually ask to repeat the words spoken by the speaker or would like to see the face of the speaker while he/she spoke or would feel difficulty in conducting conversations.

Speech disability: This referred to persons' inability to speak properly. Speech of a person was judged to be disordered if the person's speech was not understood by the listener. Persons with speech disability included those who could not speak, spoke only with limited words or those with loss of voice. It also included those whose speech was not understood due to defects in speech, such as stammering, nasal voice, hoarse voice and discordant voice and articulation defects, etc.

Locomotor disability: A person with - (a) loss or lack of normal ability to execute distinctive activities associated with the movement of self and objects from place to place and (b) physical deformities, other than those involving the hand or leg or both, regardless of whether the same caused loss or lack of normal movement of body – was considered as disabled with locomotor disability. Thus, persons having locomotor disability included those with (a) loss or absence or inactivity of whole or part of hand or leg or both due to amputation, paralysis, deformity or dysfunction of joints which affected his/her "normal ability to move self or objects" and (b) those with physical deformities in the body (other than limbs), such as, hunch back, deformed spine, etc. Dwarfs and persons with stiff neck of permanent nature who generally did not have difficulty in the normal movement of body and limbs was also treated as disabled.

Rationale of the Study

The social model of disability takes the view that individuals are disabled, not by their physical, sensory or mental impairments but by the structure and organisation of society. This means the category Disabled people, as well as referring to all forms of physical and sensory impairment, includes people with mental health problems and learning difficulties. This definition of disability entails variety of impairment and the access and inequality in healthcare services will manifest in different ways for different people. It is universal observed phenomena that the people affected by one dimension of deprivation are more likely to experience multiple deprivations. Often these people are placed at the margins of the society and experience discrimination and exclusion while planning and implementation of various health programmes and are particularly at the risk of poor health. These groups of peoples have particular health needs, yet experience more difficulty in gaining access to health care. Due to such marginalization such groups are more vulnerable for as the lack the opportunity to exercise wide range of human rights, including right to political participation, health and education. *Vulnerability* within the right to health framework means deprivation of certain individuals and groups whose rights have been violated from the exercising agency (Yamin,2005). Among these groups of people are the disabled of the country who are disadvantaged as compared to others mainly on account of their reduced access to medical services and the underlying determinants of health. For example, persons with disabilities often don't get employment or adequate treatment, face various forms of discrimination that affects their health and reduces their access to health services.

Disability poses greater challenges in obtaining the needed range of services. Persons with disabilities face several forms of discrimination and have reduced access to education, employment and other socioeconomic opportunities. In India, there is an increase of proportion of disabled population. The proportion of disabled population in India is about 21.9 million. The percentage of disabled population to the total population is about 2.13 per cent. There are two broad categories of disability, one is *acquired* which means disability acquired because of accidents and medical reasons the other is *disability since the onset of birth*. According to the National Sample Survey Organisation Report (58th Round), about one-third of the disabled population have disability since their birth. There are interstate and interregional differences in the disabled population. The disabled face various types of barriers while seeking access to health and health services. There are different types of disability and the needs of the disabled differ accordingly. Among those who are disabled women, children and aged are more vulnerable and need attention.

In recent years a lot of focus has been placed on the rights and health of the disabled both at the international and the national level. A part of these efforts addressing the issues of the disabled was 'The Person With Disability Act 1995',commonly referred as PWD Act which came into force on 7February,1996. The act revolves around the themes of Equal Opportunity, Protection of Rights and Full participation of the disabled. However with almost 16 years of work done following the implementation of act, the realization of its objectives must be evident in various social facilities including health systems. However field realities

reflect a different picture and hence there is need to evaluate how successful the system has been in addressing the health needs of the disabled and explore the gaps existing in the current health system for future planning .

Title of the study:

To assess the healthcare need of the Persons with Disability and find the gap in health service provision for the disabled of the Nindura Block of Barabanki District, UP.

Objective of the study:

1. To study and assess the healthcare needs of the disabled
2. To assess the available public health facilities in the block
3. To find the service gap in healthcare service provided

Methodology of the study:

Study population: For the study the area served by SPARC-India in its Rural CBR programme will be covered. As Rural CBR program has been working in 12 Gram Panchayats, the study will try to assess the health needs of the disabled population in the said area. As per the survey made by SPARC-India the details of Disabled person in the area is as follows.

PWD's in the rural area where the organization is working (Nindura Block, Baranbanki District, UP).

The total number of identified PWDs in the area is 476.

Physical	276
Mentally retarded	74
Blind	27
Deaf	36
Multiple	63
Total	476

Universe / Study Population:

The study population includes all the Disabled persons identified in the area served by the Rural CBR program of SPARC-India in Nindura Block.

Sampling Frame:-

For the study purpose we are taking 6% of the population as a sample. The sample is inclusive of all the types of the PWDs. Considering 6% as population the sample is

Physical	17
Mentally retarded	4
Blind	2
Deaf	2
Multiple	4
Total	29

Sampling Procedure:-

The sampling procedure will as purposive sampling.

Data collection tools:

- Interview schedule for disable persons
- Focus group discussion among the members of Disabled Persons Organization
- Interview guide for Key informant Interview

Data collection methods:

Both qualitative and quantitative methods are used for data collection.

- Qualitative methods include: FGD and key informant unstructured indepth interview.
- Quantitative methods include: interview of PWDs with interview schedule using questionnaire attached in the Annexure.
- Secondary data from block office and Community Health Center/PHC

Source of data:

1. For quantitative data: PWDs of each type above 18 years.
2. For qualitative data:
    - Key informants – medical officers
    - For FGD: Members of DPO/SHG

Analysis Plan:

The collected data will be analysed by using software SPSS and qualitative data will be used for supporting quantitative data.

Analysis

Charateristics of the respondents covered

Following is the characteristics of the respondents covered in the study

i. **Age groups:**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0-15	6	20.7	20.7	20.7
	16-30	14	48.3	48.3	69.0
	31 and above	9	31.0	31.0	100.0
	Total	29	100.0	100.0	

Most of the respondents belongs to the age group of 16-30 years.

ii. **Sex of the respondent:**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	male	22	75.9	75.9	75.9
	female	7	24.1	24.1	100.0
	Total	29	100.0	100.0	

About 75.9% of the respondents were male.

iii. **Education of the respondent**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	8	27.6	27.6	27.6
	1	2	6.9	6.9	34.5
	2	1	3.4	3.4	37.9
	3	2	6.9	6.9	44.8
	5	2	6.9	6.9	51.7
	6	2	6.9	6.9	58.6

	7	1	3.4	3.4	62.1
	8	3	10.3	10.3	72.4
	10	4	13.8	13.8	86.2
	12	2	6.9	6.9	93.1
	15	1	3.4	3.4	96.6
	17	1	3.4	3.4	100.0
	Total	29	100.0	100.0	

As it is evident that the literacy level in the area served is on the lower side which is reflected in the above table as 27.6% are illiterate. The educational level also plays an important role in the utilization of the health facilities as the information barrier is the biggest challenge in improving the utilization rate especially in the areas observing low literacy rates.

iv. Religion

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Hindu	22	75.9	75.9	75.9
	Muslim	7	24.1	24.1	100.0
	Total	29	100.0	100.0	

About 75.9% of the respondents were Hindu while the rest were Muslims.

v. Type of disability the respondent is suffering from:

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	physical	17	58.6	58.6	58.6
	MR	4	13.8	13.8	72.4
	HI	2	6.9	6.9	79.3
	VI	2	6.9	6.9	86.2
	Multiple	4	13.8	13.8	100.0
	Total	29	100.0	100.0	

Since the sample was purposefully drawn from the identified PWD's in proportion most of the respondents were Physically handicapped (58.6%) followed by MR and Multiple disability.

vi. **Monthly Family Income-**

The monthly family income of the respondent averages to about Rs.2596. The monthly income of the family is very important as it allows us to evaluate the affordability of the available health services.

vii. **Personal Income of the disabled-**The average monthly income of the respondents is about Rs.517. It reflects not only how dependent the disabled person is on the family members, but also indicates the level of independence that a person with disability could achieve if he could afford the required health services needed for his rehabilitation .

viii. **BPL status of the family:**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	21	72.4	72.4	72.4
	No	8	27.6	27.6	100.0
	Total	29	100.0	100.0	

As the region is economically backward most of the families (72.4%) belongs to BPL families.

ix. **Relation of the disable to any organisation:**

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	23	79.3	79.3	79.3
	No	6	20.7	20.7	100.0
	Total	29	100.0	100.0	

The good practice standards indicate that the involvement of the person with disability or their families in the Planning, Implementing and the evaluation of the programmes or initiatives for improving the health of PWD's is an healthy sign. With the respondents association with the any organization we are trying to assess the possibility of achieving the same in near or distance future.

A. Availability:-

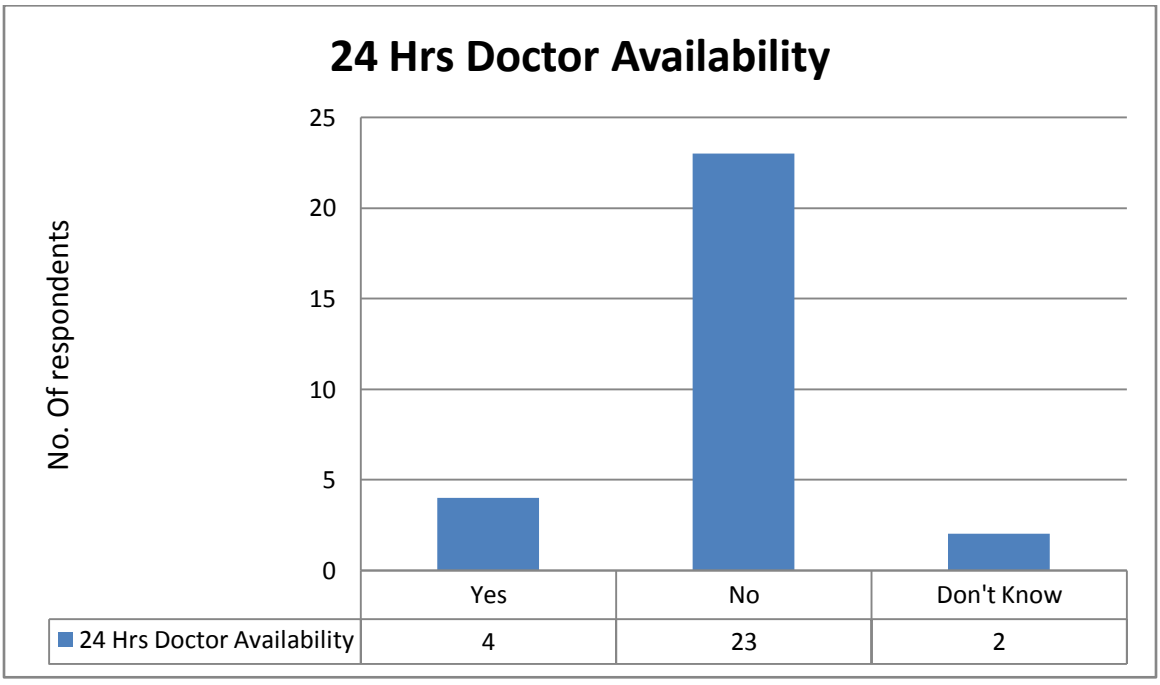
Following is the list of Health centres available in Nindura Block

1. Anwari- PHC
2. Belvahar- PHC
3. Ghunghter- CHC
4. Kursi- PHC
5. Thakure Mau- PHC

Does the health centre is open for all throughout the year?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	yes	29	100.0	100.0	100.0

Are doctors available in the health centre for 24hrs?



a) A)General Medical care

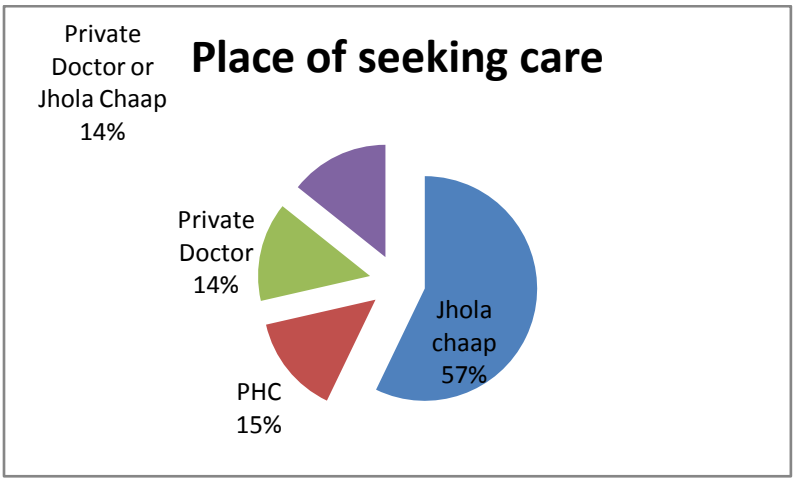
- All of the respondents were aware of the nearest health care centre available, which means the influence of information barrier for accessing health care is minimal.

However the utilization of the health services is also influenced by other factors which will be explored further in the study.

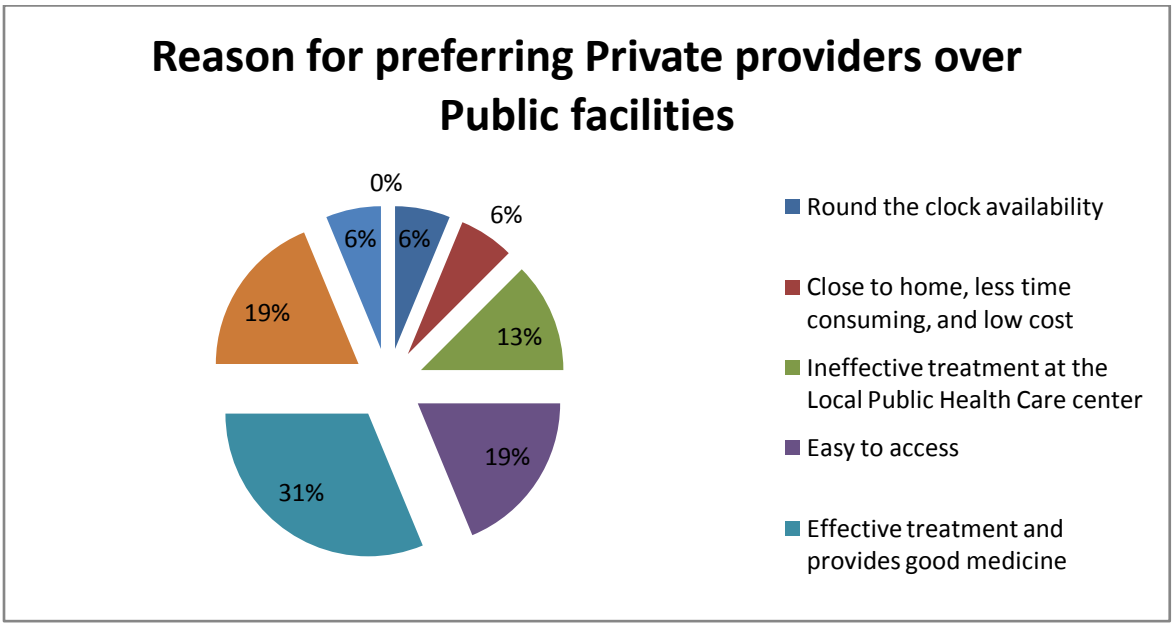
- As per the findings of the study, there was no PHC located within the villages of the respondents. Furthermore, on an average all the respondents had to travel at least 1-2 Km for availing health services from the nearest PHC/CHC.
- As far availability of health services are concerned the awareness of the kind of services/facilities available at these centre is low. All of the Health facilities reported by the respondents provided throughout the year without fail which is encouraging finding for development of better health services in the future. When asked about availability of doctors at these centre, there was a slight deviation in the findings which suggested that the though the facility runs throughout the year, the doctors were not available round the clock which severely affects the utilization pattern of Public facility observed in the region.
- About 82% of the respondents reported that the doctors are not available at the respective centre round the clock. The doctors are available only for a limited amount of time and regularly conducts OPD during these hours. The timings of OPD vary from 10 A.M to 4 P.M in the evening. As per IPHS Health standards applicable to these facilities, these facilities should provide 24 hour service to the population it serves. This is reflecting a huge service gap existing in the community based health services.

Due to this community prefers Private providers over public facility which is evident in the findings of the study which indicates the failure of the system to provide high quality of care to the community at their doorstep. This finding also fails the objective of the Health system to provide high quality general medical services to the disabled.

Place of care:



Reasons for receiving care from Private providers:



The main reasons cited by the respondents for their choice of private providers over public facility are Low cost of treatment, closeness to their home, easy to access, round the clock availability, effective treatment and ineffective treatment at public facility. All of these reasons points to the failure of the system to provide health services of acceptable quality, easily accessible (located close to the community), affordable and available round the clock.

The above findings clearly indicate the loopholes in the provision of medical services to the population. Such findings are discouraging considering the achievement of objectives of UNCRPD which provides the disabled with the right to health through provisioning of services equal to others. However if we consider the state of health facilities in the region the health system is failing to provide comprehensive health services to even normal population.

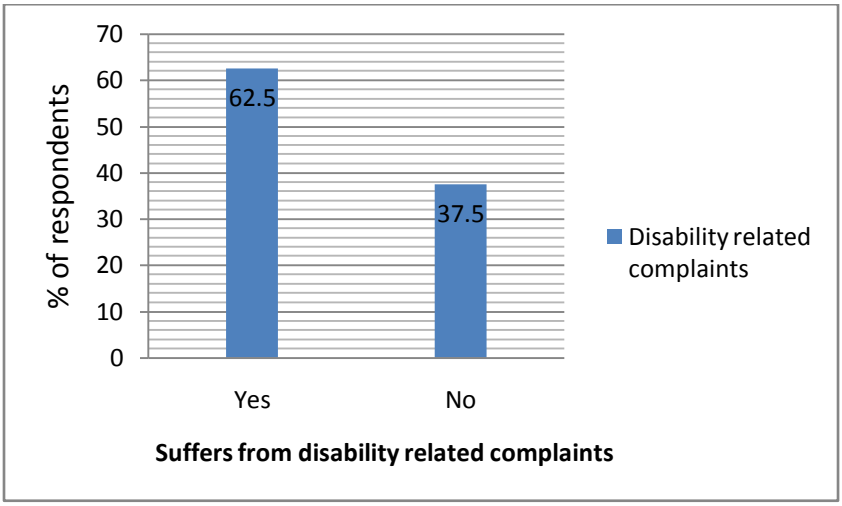
b) Targeted Services-

As per the WHO standards for providing Healthcare services to the disabled, the health system should provide for general as well as targeted services to the person with disability to satisfy the specific health requirement of the disabled which include Specific Medical care, the Rehabilitative and the Support services.

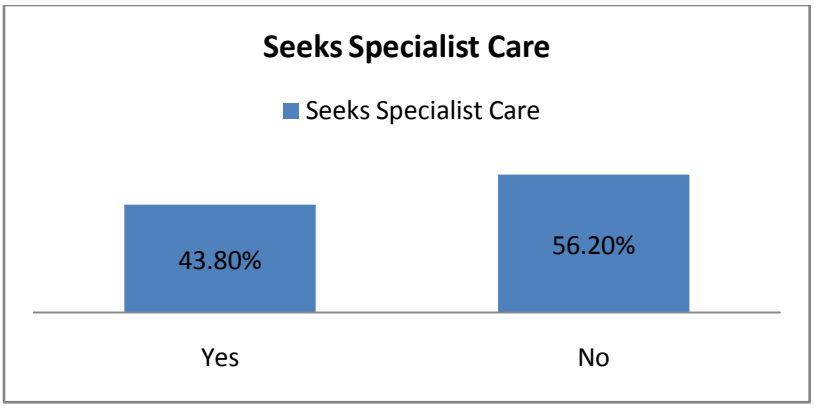
Specialised Medical Care-

As per WHO good practice example the specific health services addressing the health needs of the disabled should be provided free of cost through the primary Health Care Model. However on assessing the current situation in the area served by SPARC-India, there is no provision of specialized care at the PHC level. Such specialized care are only available at the city hospital which are Ram Manohar Lohiya Hospital or the other tertiary care hospitals. Though doctors are available at the PHC which provides primary level care but the medicine required for treatment of disability related health problems are not available at these centre and are to be bought from private medical stores. Furthermore WHO good practice criteria include provision of programmes of early detection, diagnosis, assessment and treatment of the disability. Though some activities related to the above objectives are carried out at the grass root level there is no specific health programme providing for the above mentioned theme of services. Another example of good practice identified by the WHO is the provisioning of information through effective means of communication such as easy to understand charts, sign language and face to face communication . Such type of initiatives for dissemination of information for prevention and early diagnosis of the conditions leading to disability is critical which is lacking in the current efforts for prevention of disability.

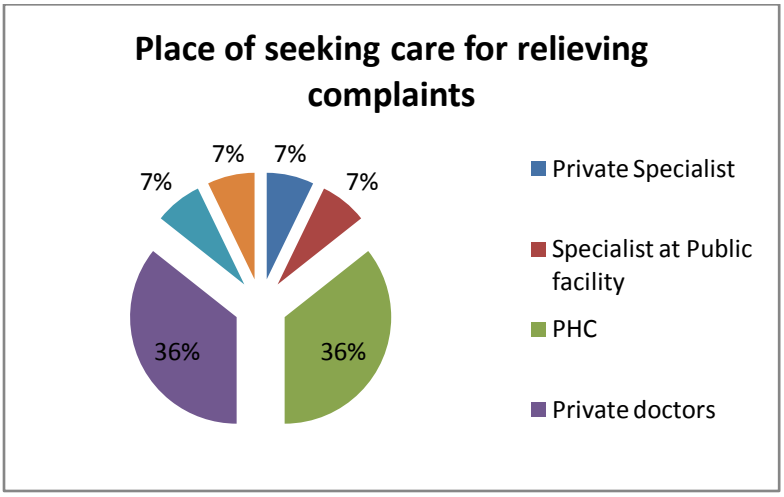
Disability related complaints:



Specialist care for the complaints related to Disability:



Type of Care availed for the complaints related to Disability:



- As per the findings of the study 62.5% of the respondents reported some health problems /complaints related to their disability. Out of these 62.5% only 56.2 % do not seek medical care for their health problems, whereas ideally all the respondents should receive medical care for such complaints. This may be due to treatment seeking behavior of the individual or the non-availability of specialist care in the region.

- While out of the rest of the 43.8% who seek medical care for disability related complaints, only 43 % of the respondents avails medical care from public facility. Out of this 43% only 7% avail specialist medical care from public hospitals while the rest 36% consult the PHC doctors for symptomatic treatment of their complaints.

The main reason for such finding is that the specialist care is available only at the tertiary level hospitals and those hospitals are located in the city which is about 30Km from the

community. The location of these hospitals placed at larger distance from the community hampers it physical accessibility for the disabled person, as it is very difficult to commute in the due to limited means of transport. Due to larger geographical distance, these hospitals are inaccessible for most of the BPL families as the travelling cost involved in availing special care from these hospitals are unaffordable. Hence most of the respondents seek private care for the disability related complaints.

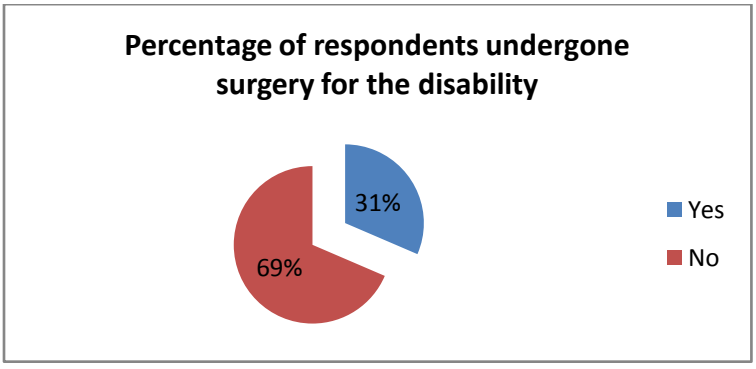
- As per the data collected the main reason for such treatment seeking behavior was found to be Easy accessibility and low cost of private providers which are mainly the village local doctors (Jhola chaap). Another reason that was found is the recommendation of relatives and friends.

These findings reflect the gap that exists in the accessibility, affordability and the information dissemination of the available health services.

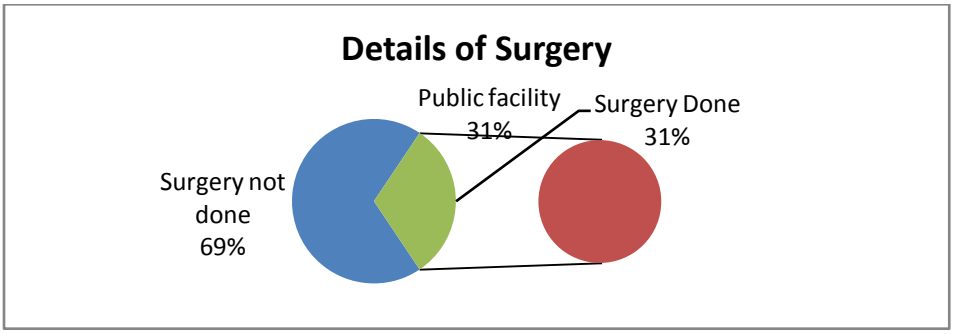
According to WHO good practice standards for providing health services to the disabled, the targeted care should be located in the community so that it is easily accessible. Also it instructs that such care should be provided free of cost, but due to inappropriate location of the services, the community has to bear transport cost as well as opportunity cost which makes unaffordable to the BPL/marginalized families with disability.

Lastly these standards emphasize the need of dissemination of the information about the available services to increase its utilization by reducing the informational barrier. Though as per the findings the awareness of the location of the nearest Public health facility is exceptional, the awareness regarding the hospitals or the facilities providing specialist/ targeted services is significantly low.

Surgical Care:



Place of Surgical care:



- Among the respondents only 31% of the respondents had undergone any surgery for their disability.
- Out of the respondents who had undergone surgery for their disability only 31.3% of the surgeries were performed at the public facility. This indicates the rate of utilization of the surgical facilities at the Public Facilities.

In the country where the approach of the state is of Welfare State the public facilities should have been able to provide for these services to at least 50% of the targeted population.

As per the findings of the study these decision of the place of these surgeries were influence by the following factors-

1. Decision of the family
2. Recommendation of the friends
3. Low cost of treatment.

It is discouraging to know that none of the respondents reported that they have opted for the public facility due to the quality and effectiveness of treatment provided at Public facility.

The WHO standard entails the aim of providing high quality of Specialist care for the disabled which is lacking in the current health care scenario in the region.

Availability of effective and equipped trauma care centre is core requirement in the programme/initiative to prevent Disabilities which is lacking in the area. Though there are private trauma care centre available in the region but the financial accessibility of the same is the barrier which most of the BPL families are unable to overcome.

Apart from the specialized medical services the health system should also provide for Rehabilitative and Supportive care.

Provisioning of information and communications is critical as the lack of awareness of the available facility is the major reason for underutilization of the services.

I. Rehabilitative Services

The rehabilitative services should provide for local community based rehabilitative program or services to enable all people with disability to reach their optimum level of independence and functioning. However such rehabilitative are only available at the tertiary level hospitals.

- Rehabilitative are only available at the tertiary level hospitals.
- These tertiary care hospitals are located in the city and are at a fair distance from the villages. Such services should be located as close as possible to the community which is a major gap considering the extent of physical and the financial barrier that such type of services possess.
- There is a lack of rehabilitative program for capacitating the disabled to lead a more independent and productive life. To be more participative in the social activities and contributing towards society is one of the objectives of UNCRPD. UNCRPD provides for providing the disabled with an enabling environment which requires such rehabilitative program.

Lack of rehabilitative services could have lead to a more challenging situation for the disabled if it hasn't been for organization such as SPARC-India which are providing these services through their Rural CBR program.

II. Support Services-

The Support services should provide for following-

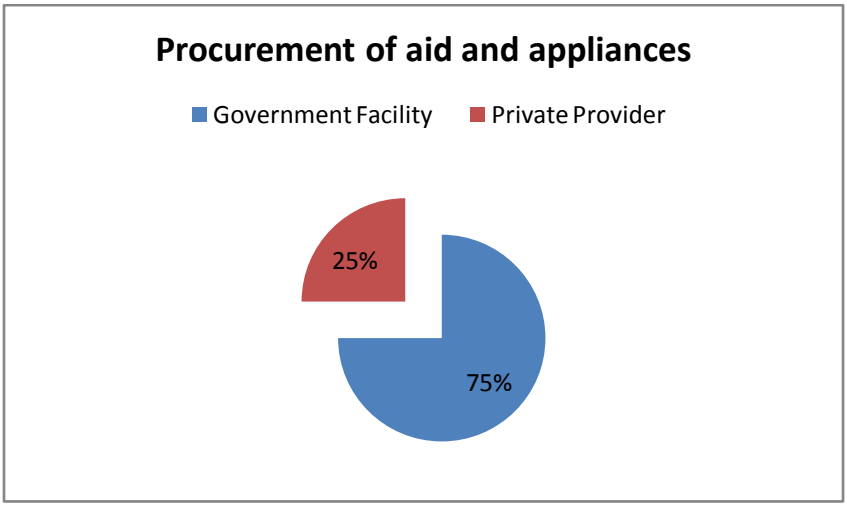
A. Access to assistive devices free of cost
B. Community based and home based support
C. Financial support to carers and to families with children with disability.
D. Distribution of the equipment and dissemination of the information about them.\

Aid and appliances needed:

Out of the sample selected for the study 66.6% of the respondents were advised Aids for their disability, however only 50% of the total sample was actually having the advised aid/appliance.

The reason cited by the rest of the 16.6% of the respondents for not acquiring the prescribed aid/appliance is the cost of appliance being very high.

Procurement of aid and appliances:



If we take a look at the place of procuring the prescribed aids and appliances,

- Out of the 50% of the respondents that were using disability aids/ appliances, 75% of them have procured it from government schemes and facilities while the rest have purchased from private medical stores.
- Out of those who have purchased the aid from private medical store, the respondent have incurred an expenditure of Rs.2,500 for Hearing aid while the other respondent had incurred a cost of Rs.850 for crutches and walking stick.
- There were some respondents who had been advised to use some of the disability aids devices and have not acquired it as they are not able to afford it, which may reflects a gap in provisioning of the support services.

The observation may be due to lack of information of the services targeted at such individual. In both the cases there exist a gap in the provisioning of the services either provisioning of actual service or the dissemination of the information of the service which may influence the actual effectiveness, coverage and utilization of these services.

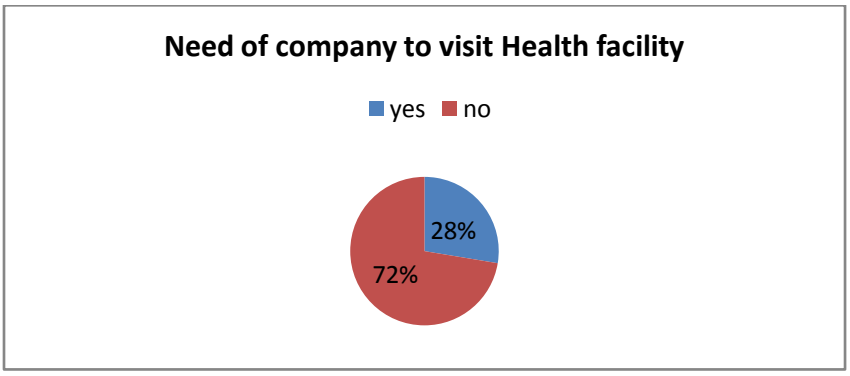
B. Accessibility

Accessibility is one of the most important parameter for assessing the effectiveness of the health system in provisioning of the services. The health system should aim at providing fully accessible services in both mainstream and targeted services for the person with disability. However to achieve such objectives the health services should be as close as possible to people's own community especially in the remote areas where the accessibility of the place is major concern cornering the objective of providing high quality services.

Health facility	In Village	Less than 1km	1-3 Km	3-5 Km	Greater than 5 Km
PHC	6	0	10	35	81
Ayurvedic Dispensary	1	0	2	15	114
Unani Dispensary	1	0	1	10	120
Homeopathic Dispensary	4	0	11	29	88
Sub centre (FWC)	11	0	18	41	62
Mother-child Welfare Centre	92	0	31	8	1

Source –Sankhyiki Patrika

Does the PWD needs assistance to reach to health centre?

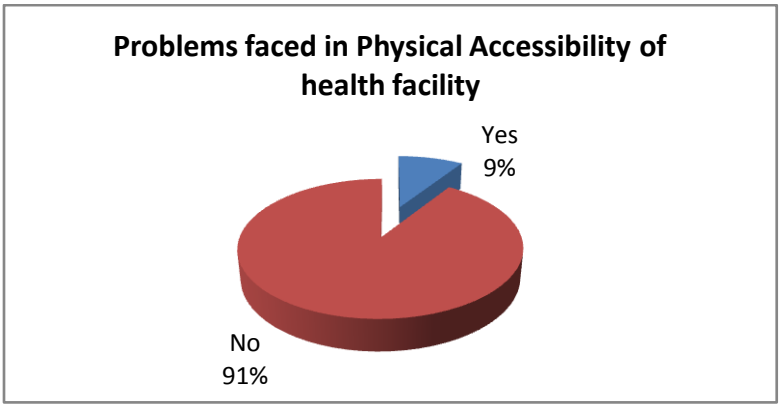


On exploring the need of company for visiting the nearest Public healthcare facility-

- 28% of the respondents needs company.
- This reflects the opportunity cost that may be involved in accompanying the person with disability to the hospital /health center. For the opportunity cost to be low, the

center should be located as close to the community as possible. Also the center should be well equipped with instrument and staff for providing quality services. If these centers are not well equipped then problems like high waiting time , high opportunity cost and low satisfaction level may be reported which may ultimately lead to lower utilization of the services

Physical accessibility problem:



i. Physical Accessibility-

Most of the villages included in the study do not have health center within their village but are located at an accessible distance for normal population.

- On an average an individual has to travel about 2 km to reach to these centers. When the physical accessibility of these centers is assessed for disabled population then these centers score on a lower scale. The system should plan for placing these centers closer to the community.
- As per the finding of the study most of the centers available in the region are accessible to general as well as disabled population. Only a few of the centre pose the problem of accessibility during the monsoon season as the road to these centers are cut off due to water logging. However such problems do not pose a major threat to the accessibility of the centers.
- Since the buildings of these centers are not huge and complex, the physical accessibility is not the issue faced by the disabled.

Specific care

- Specialized care are only available at the city hospital which are Ram Manohar Lohiya Hospital or the other tertiary care hospitals.

- These hospitals are located at a distance of about 30-35 Km from the village and due to inadequate means of transport the accessibility of these centers are seriously curtailed for the disabled.
- Though the doctors available at the PHC provides primary level care but the medicine required for treatment of disability related health problems are not available at these centre and are to be bought from private medical stores.

ii. Information accessibility

Information Accessibility is one of the major determinants of the extent of utilization of the available health services.

- Though the all the respondents were aware of the nearest Public Healthcare facility, but the awareness of the services available at these centers was quite low.
- For specialized care, the awareness about the availability of these services is negligible and requires to be improved by reducing the Informational barrier for utilization of these services .
- Also the community unaware of the charges that is applicable to the services provided at these centres and are generally exploited by the PHC doctors.

Among the malpractices that were reported the practice of demanding money for effective medicines by the doctors at PHC's was reported on several occasions. The justification provided by the doctors for charging for the medicines is that these medicines have been procured from private medical store as the medicine available through central drug distribution system are either not effective or have not been received yet.

iii. **Economic accessibility (affordability) –**

As per the rule the patient at the PHC should be charged at Rs.2 per patient. However the doctors at the PHC charge the patients for the medicines. As per the reason provided by the doctor for the fees, the prescribed medicine is either not available or is not provided under the central drug distribution mechanism and are hence procured from private medical stores.

If the cost of availing treatment at the facilities is concerned, the opportunity cost such as loss of wages due to company needed by the disabled, travelling cost and other cost must be accounted. Considering the economic profile of most of the respondent, the indirect cost involved in availing specific treatment from public facility is too high. This indirect cost includes travelling cost and loss of wages.

Among exploring the event of denials among the respondents the most evident reason was denial based on financial ground.

Though it is recommended by WHO standards that all services for the disabled should be provided free of cost, the implementation of such mechanism is not visible in the current health system scenario.

As per the findings of the study, 3.4% of the respondents faced financial barrier in availing medical care from the facility.

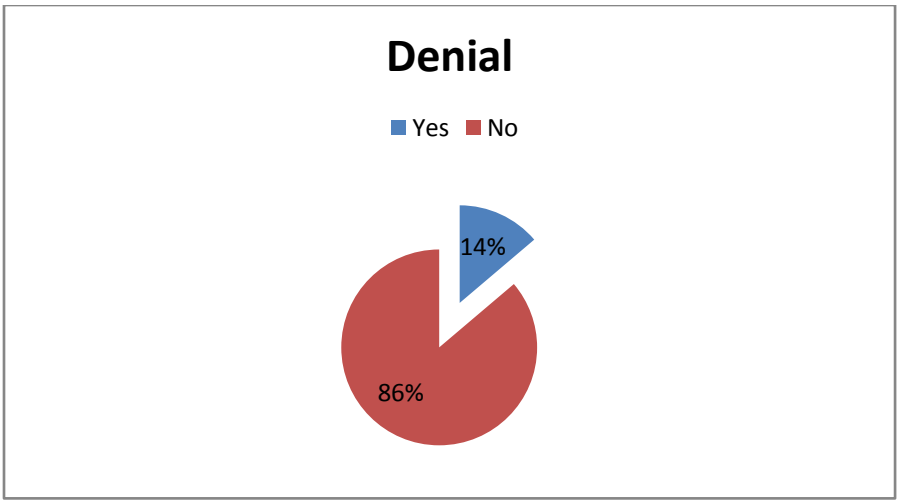
Cost of care:

In the study the cost involved in getting a specialist care was explored. As per finding of the study the cost involved in getting specialist care varies from as low as Rs.100 to as high as Rs.4,500. The former is the case when the services are provide through public facility at free of cost and medicine or aid is provided at concessional rates. While the latter exhibit the case when a family avails services from private provider where no concession is provided. These two ends of the cost scale highlights two situation. One is the cost one has to bear if good quality services are provided through public facility and the other when public facilities fails to provide specialist care to the targeted population. In the latter case the amount of expenditure incurred for availing services from private providers highlights the threat of catastrophic expenditure that is looming on the families with disability.

- About 12.5 % of the respondents had not undergone the advised surgery due to the cost involved in the surgery which was unaffordable.
- The reason cited by 16.6% of the respondents for not acquiring the prescribed aid/appliance is the cost of appliance being very high.

Non-discrimination - Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner.) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

- On exploring the occurrence of any kind of Discrimination, 96.6% of the respondents did not report any kind of discrimination which is a good sign for the future as discrimination may lead non-utilisation of the services

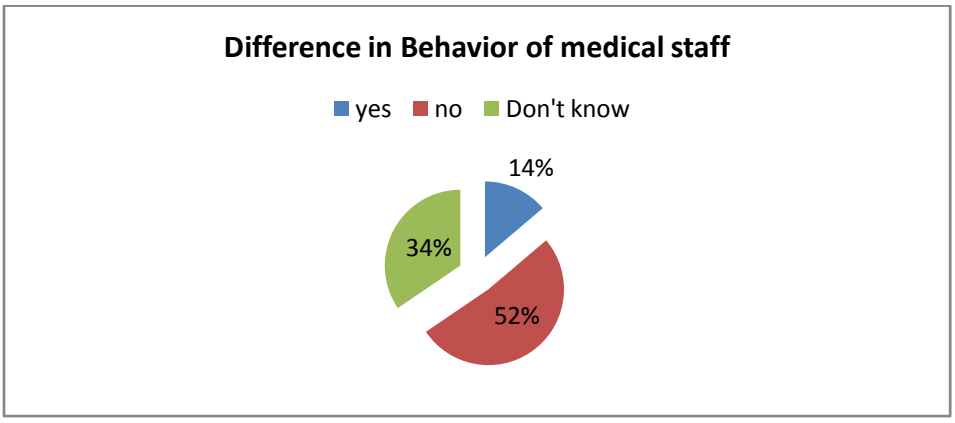


- About 14% of the respondents have faced denial of treatment. The main reason for the denial of treatment is on financial grounds.

Provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education;

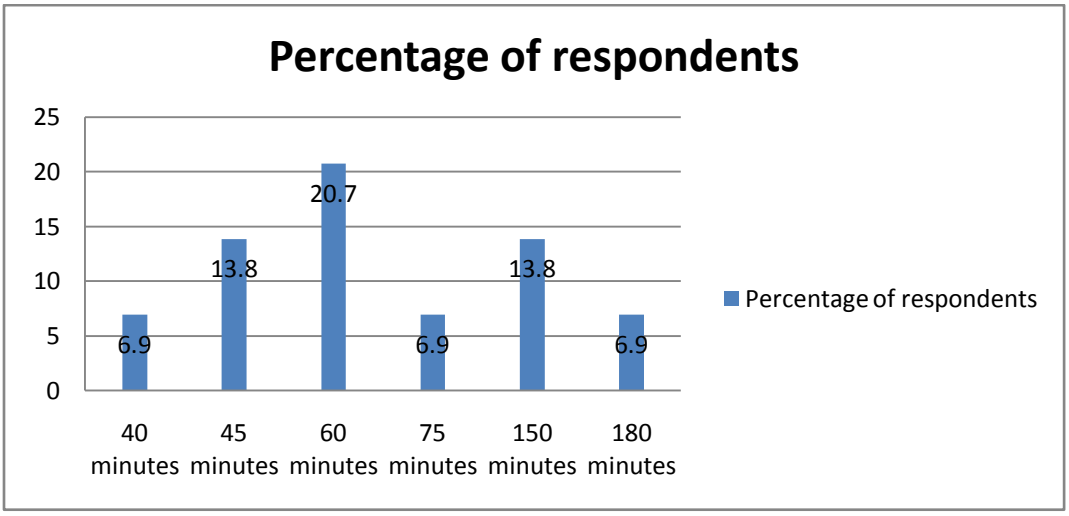
C. Quality of services

As per the standards the facility should provide same quality of services to the people with disability.
The quality parameters include the behavior of the staff with PWDs, low waiting time and good quality of treatment. Following are the findings for the respective parameter.



- As per the findings 14% of the respondents reported difference in the behavior but all the reported difference was explained to be better than the others.

Time spent in minutes for availing treatment from Public facility:



- Most of the respondents about 21% reported that the time spent for seeing the consultant at the public facility is about 60 minutes.
- The average waiting time in the public facility was found to be 111 minutes which is on the higher side considering the need of the disabled to be accompanied by someone and the subsequent loss of pay associated with their visit to the center.

Among exploring the problems faced by the respondents in availing treatment from the public facility the following problems were found-

1. Doctors do not attend the patient in time
2. Treatment is not effective
3. Low quality of Medicine
4. Doctors prescribe medicine from outside

Conclusion:-

On reviewing the existing condition of the health services and policies that are specific to person with disability, there exist gaps both at the policy level as well as at the implementation level.

- At the policy level the PWD Act 1995 fails to provide commitment for provisioning of specific health services for the PWD's.

- The policy says that the quality of services provide to the PWD's should be at par with the services provided which lacks commitment to provide quality services to PWD's if the services provided to general population lack quality. With such statement the policy exhibit lack of understanding of the specific challenges that are faced by PWD's.

- At the implementation level the services available for the Person with disability is not up to the mark. However the finding is not specific to the PWD's but can be generalized to entire population of the block.

- The services fail to fulfill most of the criteria laid down by the WHO provided standards for provisioning of health services for the PWD's.

- The services fail to provide specific care through the Primary Health Care model.

- There is a lack of rehabilitative services close to the community.

- The effectiveness of support services are hampered by the gruesome certification process and the lack of distribution channel of aids and appliances for the PWD's.

- The specific services should be provided free of cost is the instruction provided for providing affordable services that are accessible for even the marginalized and vulnerable group of people . however the opportunity cost and indirect cost involved in availing such treatment are never accounted for in determining the affordability of the services.

- The implementation of the National programmes such as National Pulse Polio Programme, National Iodine Deficiency Disorder Control Programme , National Leprosy Eradication Programme and National Blindness Control Programme lacks focus in prevention of acquired disability.

- The dissemination of information of various schemes and available services in the facilities are not adequate and lacks coverage.

- There is an absolute lack of outreach programmes such as surgical camps etc.

- The hospital infrastructure fails to provide enabling environment for improving the accessibility of the structure for PWD's.

- Awareness of the providers about the entitlements of the PWD is low.

Focus group:

For qualitative data collection a focus group was conducted on September 7, 2011 at Rural CBR office in Nindura. The FGD was conducted among the members of DPO and Uday Vikalang Manch.

Time – from 2:30 pm to 3:15 pm

Participants: participants for the FGD were members of DPO and Uday Vikalang Manch. The number of participants for the discussion were 11 among which 4 were female. All the participants were disable persons. They included Physical disable, Hearing impaired, Visual disable and Multiple disable.

Focused area for discussion:

The discussion was conducted for need assessment of the disable persons for the health care. The discussion was focused on –

- Health needs of the disabled
  - Primary or general care needs
  - Needs specific to their disability
- Awareness about available facilities
- Health or treatment seeking behavior: how, when and from where they seek care
- Health care service utilization: from where and why they seek care from particular facility
  - Accessibility : barriers
    - Geographical
    - Informational
  - Availability
    - Services
    - Staff
    - Medicine
  - Affordability – economical
  - Acceptability – perceived quality of care, Behavior of the staff
- Suggestions for the available facilities

Discussion:

- Health needs: All members in the discussion discussed about their health need and difficulties face by other disabled.

- The major primary needs were – illnesses like fever, cough cold, abdominal problems, body ache, weakness etc.
- The special health need – these included the pain and weakness in the disabled part of the body, disability related surgical needs, need for aids and appliances like crutches, tricycle, artificial limb, spectacles, hearing aid etc.
- All the participants were well aware about the physical availability of the health care services present in the area. the facilities they e were knowing about are PHCs, CHC, AYUSH dispensaries, private hospitals, private dispensaries, Local (zolachhap doctors), traditional healers etc. some of them were also knowing about the tertiary care treatment facility in district headquarter and Lucknow.
- Generally the disable person does not seek care immediately after illness but they need to wait till someone accompanies or gives money to them to seek care.
- For seeking care many of the disabled are dependant especially the CWDs, disable females, mentally disabled, multiple disabled and few physically disabled people.
- Very commonly the disable seek care from local doctors and traditional healers for their primary needs. Very few of them visit to public health care facility (as there are many issues related). For specialized care, these disabled either visit to the state tertiary care hospital in the capital city or the private specialists in the city.
- The utilization of facility for primary care is mainly due to the economical reasons (due to less expenditure in treatment from local doctors, readily availability, no transportation needed and bribery in the public healthcare system). Utilization of specialized care from the specific facility is due to unavailability of the services in any of the facilities available in the area and it also dependant on the financial condition of the family (poor families visit government centers while a better family visits private specialist).
- Accessibility: the public healthcare facilities are available at very few places and are not easily accessible. The villages are connected by road but means of transport are not readily available to reach the facility.
- Availability: Availability of the physical facility is well known to the community but they are not able to tell about the services provided through the center.
- The staff especially doctors at any center (dispensary/PHC/CHC) are available only at for 4 to 6 hrs in a day (from 10 AM to 2 or 4 PM). There is no doctor available for 24 hrs.
- Medicine is also a point of concern and related to bribery in these facilities. All participants reported that in the PHC and dispensary, the staff asks money for providing the medicine. And the amount is much higher than at the local; doctors. If the patient refuses to pay the amount then only general medicines are given and good medicine is not dispensed.
- Affordability: The cost of care for taking treatment from public healthcare facilities is higher than that of local doctors. The cost involves both direct and opportunity

cost (cost of accompanying person) for the public healthcare facilities. Wherein the local doctors are readily available and they charge small amount (Rs 10 or 20) for a single visit.

- For the specialized care, surgical intervention and aids and appliances the cost involved is very high and many of the disabled are not able to bear the cost. So they are still deprived of the specialist care or have not completed the care due to the affordability.
- Acceptability: the quality of care is major issue in the acceptability. The perceived quality of care in the disabled is very poor. They reported that the quality of care depends on the affordability of the individual. Those who will pay for the service will get good quality of care as well as good medicines. Concept equality of care for all is lacking here.

Suggestion from FGD:

- Availability:
  - ✓ Doctor should be available round the clock.
  - ✓ All medicine must be available at each level of public health care service.
  - ✓ Proper infrastructure for sitting and accessing the building (slanting slopes instead of steps etc)
- Accessibility
  - ✓ Physical accessibility should be improved
  - ✓ Accessibility for specialized care should be improved
  - ✓ Specialized care should be available for the disabled at least at the CHC level and if possible then at PHC level.
  - ✓ Separate counters and queues for disabled
  - ✓ Travelling facilities must increase to decrease the geographical barrier
  - ✓ OPD's must be located at ground floors to provide easy access to the same for the disabled.
- Affordability
  - ✓ Economic concession or free consultation and medicine
  - ✓ All consultation, all kind of treatment should be available at the cost as per rule or free of cost
  - ✓ Some concession on the basis of disability and BPL status
- Acceptability
  - ✓ Good quality of medicine must be given
  - ✓ Good behavior of the doctors and staff
- Support services
  - ✓ Aids and appliances should be provided

- ✓ Ambulance should be provided for emergency care
- ✓ Trauma care unit in the region.

Recommendations:-

'The right to health does not mean the right to be healthy, nor does it mean that poor governments must put in place expensive health services for which they have no resources. But it does require governments and public authorities to put in place policies and action plans which will lead to available and accessible health care for all in the shortest possible time. To ensure it happens is the challenge facing the human rights community and public health professionals.'

Mary Robinson,
Former UN High Commissioner for Human Rights

1. **Enhancing efforts to prevent Disability:** Within and outside health sector

2. **Improving early identification and certification of disability**: Improved coordination with ICDS; Locally relevant Screening tools

3. **Improving access and quality of Rehabilitation Services:** Raising awareness of health workers about disability; Enhanced supply of providers; Partnerships with NGOs; incentives for low cost and locally relevant technologies.

4. **Two phased approach:**

   I. Improve certification system, promote CBR (including awareness raising and stigma reduction), and enhance micronutrient supplementation (including food fortification) and immunization.

   II. Focus on improved referral systems between levels of the health system, including increased supply of therapists and support for establishment of therapy centers in rural areas

5. Strengthening of National programmes for prevention of disability such as Universal Immunisation Programme, Pulse Polio Programme, National Blindness Control programme, NIDDCP and National Leprosy Eradication Programme.

6. Strengthening the identification and facilitating the certification of the People with Disability.

7. Strengthening of the PHC for provision of quality care to the disabled and also increasing the available drugs at the PHC which are specific to complaints associated with different disability.

8. Building the attitude and the knowledge of the service provider as most of the providers are not aware of the entitlements of PWD's.

9. Increasing the physical accessibility of the facilities-The national institute may work on the improving the accessibility of the facility by funding various research and innovative ideas .

10. **<u>Encouraging CBR programs by providing support through policy and Acts.-</u>** Community Based rehabilitation programme has been effective in addressing the primary care and therapeutic needs of the people with disability. Surprisingly, this mode of service delivery is missing from the PWD Act. So appropriate amendments should be made to support the CBR programs as most of the programs are funded by international donors.

11. CBR should focus on building linkages of PWD's with the Village Health Committee and Rogi Kalyan Samiti.

12. **<u>Forming new act for addressing the loopholes that existed in the previous PWD Act.</u>** The health sector is the one where the PWD Act makes the weakest incremental commitments in public policy. The act mainly focuses on the early detection and prevention of the disability and raising public awareness on the issues however it does notmake any specific commitments on treatment and rehabilitation of the PWD's. Secondly in contrast to the areas suh as education and employment the act provision for the health of PWD's is limited by the lack of strict instruction . The act specifies that the provision of Health for PWD's should be done within the limits of economic capacity and development. Thus the effectiveness of Act in bringing about a change in health situation is limited to early detection and prevention of disability.

13. Constituting monitoring body at the District or at the state level to monitor the provisioning of the health services for PWD's at various levels. Also the committee will be scrutinizing the expenditure on health for the PWD's.

14. Constituting a investigation team to visit the facilities for physical accessibility of the facility for PWD's. The report of such team will be send to the Monitoring body for pressurizing the government body to make necessary changes in the Facility building/infrastructure to make it more accessible for PWD's.

15. Advocacy for earmarking certain proportion of health budget for providing services to PWD's.

16. Advocacy for inclusion of PWD's in the planning & implementation process of various schemes and programmes for PWD's.

17. Strengthening of the referral system

18. Decreasing the financial barrier for accessing the health services by placing the services close to the community and providing free services for PWD's.

19. Increasing the number of outreach activities such as screening & certification camps.

20. Strengthening distribution network for Government programs of aids and appliances, including awareness raising of among PWD and incentives schemes for producers and establishing a support center at the CHC level for provisioning and servicing of the disability aids & appliances.

21. More aggressive efforts to develop government and NGO partnership especially in the background of resource constraint faced by the Health system.

22. Continued efforts to ensure that prevention of disabilities through immunization and other preventive measures is strengthened

23. Data and statistics on disability need to be more reliably and regularly collected, in particular through strengthened NFHS and general health surveys, which have neglected disability

Plan for Immediate Action

It is understood that the gaps in health service provision for the disabled cannot be addressed on immediate basis as the comprehensive development of the existing health services will not only require infrastructure development but also requires manpower development which will take time. However the existing situation could be improved to some extent by adopting the following measures.

- Though there is an absolute lack of rehabilitative services at the community level there are NGO's like SPARC-India that have been active in the community providing them with rehabilitative as well as therapeutic services through their Rural CBR program. Health system could focus on strengthening of such initiatives by providing them with necessary support such as allowing the consultant to participate in the activities planned by the organization such as screening camps.

- The government could also allow the NGO's to start a facilitation centre that would be directly linked to the government certification process. Such an initiative would facilitate the certification process and improve the coverage of support services such pension scheme.

- The system should extend maximum support to NGO's activities such as Certification camps.

- The NGO's also provides support services in the form of distribution of aids and appliances. The government could extend support by providing such NGO's aids and appliances at concessional or subsidized rates.

- Strengthening of the Immunisation services should be one of the focus areas for immediate action plan. Universal coverage must be the goal however adequate control and monitoring measures are required to measure the outcome of such activities.

- Upgradation of the existing PHC and CHC according to the IPHS standards is required for providing quality general health care services.

- The consultant could be made available at the CHC level on scheduled days so that the outreach of specialized services could be improved.

- The government has to make a detailed plan for dissemination of the information about the existing general as well as specialized services for the disabled to improve awareness as well as utilization of these services.

Questionnaire for assessing the specific health care needs of the disabled population of Nindura Block.

- Name of the disabled person:-
- Age:-
- Sex:-
- Education:-
- Address:-
- Religion and Caste:-
- Type of Disability (along with grading if possible):-
- Monthly Income of the Family
- Monthly Income of the Disabled person if any:-
- BPL status:
- Is the PWD associated with any group or association working for the disabled?
- If yes please specify the name of the group/ association?

Awareness:

1. Which is the nearest Public Health care facility available?
2. Which are the services available there?
3. Is the centre accessible throughout the year for general population?
4. Are the doctors available round the clock throughout the year in this centre?
5. Do you think the behavior of the staff at the centre is different towards you?
6. If yes, Please specify?
7. How much time is spent for getting treatment from Public Facility?

Accessibility:

8. Do you face any kind of difficulty due to you disability in accessing care from this centre?
9. Do you need someone to accompany you to the health facility?

10. Do you face any barrier in accessing health services from this centre?
    - discrimination,
    - denial,
    - physical access,
    - financial
    - any other

Need assessment:

a. Primary care

11. Which are the illnesses that you frequently suffer from?

12. Where do you seek treatment when you get ill?

13. What is the reason for choosing the particular facility?

b. Special care

14. Do you have specific health related complaints related to your disability?

15. If yes, what is the course of action for relieving these complaints?

16. Do you have to seek care from a consultant or specialist for your disability?

17. If yes, from where?

18. What are your reasons for choosing this specific center/consultant?

19. What is the cost of availing treatment from these consultants for one episode of illness?

20. Do consultants give you any concession?

21. If yes, how much?

22. Have you undergone any surgery related to your disability?

23. If yes, where was the surgery done?

24. Any particular reason for getting surgery done at that facility?

25. Did you have any concession or any special provisions for the surgery?

26. Do you need any special equipment or accessories for your disability?

27. If yes, what?

28. How was these equipments arranged?

29. Did you have to pay for these equipments?

30. If yes, how much?

Any specific facility/service do you need/ expectation:

31. Which services or facilities do you expect to be present in the area for needs of disables?