INCLUSION OF CHALLENGED PERSONS IN RURAL SETTING

A THESIS SUBMITTED FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY IN PSYCHOLOGY

By

Amitabh Mehrotra

Under the Supervision of

Dr. Pallavi Bhatnagar

Professor

Department of Psychology

Lucknow University, Lucknow, INDIA

Department of Psychology
University of Lucknow
Lucknow, INDIA

2015

Prof. Pallavi Bhatnagar
Head

Department of Psychology
Lucknow University
Ph. 9415005819
E-mail: dr.pallavib@gmail.com

CERTIFICATE

This is to certify that Ph.D thesis entitled **"INCLUSION OF CHALLENGED PERSONS IN RURAL SETTING"** by **Amitabh Mehrotra** has been completed under my supervision and is a bonafide piece of research.

Date: 13/1/15

(Pallavi Bhatnagar)
Head
Department of Psychology
Lucknow University
Lucknow

ACKNOWLEDGMENT

I would like to extend my heartfelt gratitude to the following people who have been instrumental in helping me, in some way or other during the course of my research. Their loving, support and encouragement made this piece of the research reality.

My special regards and thanks to my revered supervisor Prof. Pallavi Bhatnagar who is also at present Head, Department of Psychology, Lucknow University. Before the good fortune of having her as my supervisor I had held her as a good enlightened teacher, dedicated to her profession. Working under her I realized that besides being a brilliant teacher she is an earnest and enthusiastic researcher as well. I am deeply indebted to her for her perseverance and her precious time which was devoted to my work. Despite her busy schedule, she offered encouragement during the rough spots and motivated me to strive for more. I especially want to thank her for the patience she has displayed towards my academic frailties and also for her constant readiness to help me. My association with her is an invaluable asset for my whole life.

I also wish to thank Prof Archana Shukla and Prof. P.C. Mishra (Ex-Head, Department of Psychology, Lucknow University) for providing me their support and encouragement during perusing my Ph.D from the department.

I pay my special regards and heartfelt gratitude to my father and my loving mother who have been always an inspiration and role model for me and stood by my side always in the tough/odd times.

I am thankful to all my colleagues, SPARC India family and team members who had contributed a lot directly or indirectly in making this work possible.

My special thanks to Mr. Rajesh Ekka, Mr. Somesh Bajpai, Ms. Shraddha Singh and above all Ms Swati Chaurasia who have provided me not only their quality time but their spirit to complete the thesis.

They have sacrificed their holidays/Sundays to be with me in my mission also for which personally I am grateful. My best wishes are always with them.

I am also grateful to my beloved family including parents, wife, children and all support staff and community members including the project staff of Deva Block, District Barabanki for encouraging and cooperating with me in undertaking the doctoral work. In case some names have been left out, also I am extending my special thanks to them.

(Amitabh Mehrotra)

Lucknow

Dated: 13 04 15

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INTRODUCTION

INTRODUCTION

"People are frequently said to be 'disabled' when they fall outside an accepted norm of function or behavior, thus the concept of disability ultimately rests upon a social judgment."

-- Sally French

DISABILITY: CONCEPT

The World Health Organization (2012) defines Disability as follows: "Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure. An activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives."

In India, different definitions of disability are introduced for various purposes and as such, they have been based on various criteria. No single standard exists in India to evaluate disability. More often different terms such as disabled, handicapped, crippled, physically challenged are used inter-changeably.

IMPAIRMENT, DISABILITY & HANDICAP

Disability has been understood differently by various cultures. Many cultures see it as a general form of punishment or gift from Gods or spirits (Stiker 1999, Ingstad and Whyte 1995).

Through volumes of theoretical and empirical researches which address the problem of disabilities, a contemporary positive change

in conceptualization is emerging in terms of the positive expressions of challenge for disability and challenged persons for Persons with Disabilities (PWDs). The ICIDH *(International Classification of Impairments, Disability and Handicaps)* provides a classification of disability in three major categories of impairments, disabilities and Handicaps (Wood 1980) being given here in brief:

Table-1.1: Classification of Disability

Impairment is "any loss or abnormality of psychological, physiological, or anatomical structure or function". Examples of impairments include blindness, deafness, loss of sight in an eye, paralysis of limb, amputation of a limb, mental retardation, partial sight, loss of speech, autism, cerebral palsy and learning difficulties.	**Disability** is a "restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being". Examples of disabilities include difficulty in seeing, speaking or hearing, learning difficulty in moving or climbing stairs, difficulty in grasping, reaching, bathing, eating, and toileting etc.	**Handicap** is a "disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual". The term is also a classification of "circumstances in which disabled people are likely to find themselves". Handicap describes the social and economic roles of impaired or disabled persons that place them at a disadvantage compared to other persons. Examples of handicaps include being bedridden or confined to home, being unable to use public transport, being socially isolated, being forced to remain illiterate.

These impairments and disabilities could be congenital or acquired, permanent or temporary. Persons with disabilities are heterogeneous comprising of many kinds of disabilities. Theoretical perspectives or models provide clarity into the meaning of the concept. Hence, the models of disability are being briefly discussed.

DISABILITY: MODELS

There are four models of disability, Moral model, Charity model, Medical model and Social model. (Bowe, 1978).

1. Moral Model

The moral model refers to the attitude that people are responsible for their own disability, which is often seen as a result of bad actions of parents if congenital, or as a result of practicing witchcraft if the disability is not congenital. This attitude can be seen as a religious fundamentalist offshoot of the original animal roots of human beings, to a time when humans killed any baby that could not survive on its own in the wild. In the terms of chronology it is the oldest model of disability. Disability is considered as punishment from God for the wrong doings of the past. Thus, persons with disabilities were treated as having committed a sin or as an alien. This extreme viewpoint construed that such people had no rights to live in the mainstream society. They were not entitled for any right to education, social life or livelihood available to other members of the society. More often the families of the disabled member were stigmatized and seen with suspicion. To avoid this, disabled people were generally hidden by their family. Neither the government nor the society was concerned with the problems faced by them. The major setback of this model was that nobody was concerned about the problems faced by the individuals with disability at their personal as well as their physical or psychological level (Bhanushali, 2007).

2. Charity Model

The Charity Model depicts disabled people as victims of circumstance, deserving of pity and compassion. This and Medical Model are probably the ones most used by non-disabled people to define and explain disability. Charity model is driven largely by the emotive appeals of charity and this model treats people with

disabilities as helpless victims needing care and protection. This viewpoint relies heavily on the charity and benevolence rather than justice and equality. The model accepts the act of exclusion of persons with disabilities from social arrangements and services in public domain. Charity model justifies the exclusion of persons with disabilities from the mainstream education and employment. Entitlement rights are substituted by relief measures creating an army of powerless individuals, without any control or bargaining power, depending either on the state allocated fund or benevolent individuals. This model advocates for social support mechanism for the benefit of person with disability. Government has been allocating large chunk of funds for the welfare of persons with disabilities as direct benefit or support to voluntary organizations. At the same time, a huge number of non-governmental organizations relying on the donations and government grants have been working for the benefit of persons with disabilities.

Another outcome of the model was that non government organizations also got involved in working for people with disability who relied on donations, government financial support or help from NGOs (Bhanushali, 2007).

3. Medical Model

The medical model of disability looks at the disabled person as the problem. It addresses disability as a problem of the person, directly caused by disease, trauma, or other health condition which therefore requires sustained medical care provided in the form of individual treatment by professionals. In the medical model, management of the disability is aimed at "cure", or the individual adjustment and behavioral change that would lead to an "almost-

cure" or effective cure. In the medical model, medical or therapeutic care is perceived as the chief concern, and at the political level, the primary answer is of making improvements or restructuring the healthcare policies (Nikora, Karapu, Hickey, & Te Awekotuku, 2012) (Cole, 2000).

4. Social Model

Impairment and chronic illness exist and they sometimes pose real difficulties for us. The social model upholds that the disabled people regardless of their particular impairments are subjected to a common oppression by the non-disabled world. As a disabled person, one is often made to feel it's his /her own fault that he/she is different. The difference is that some part, or parts, of the body or mind are limited in their functioning.

The social model of disability addresses the issue of "disability" mainly as a socially created problem, and the answer to it is social inclusion. In this model, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social environment.

Consequently under this model dealing with the problems of the disabled people, a collective action needs to be taken by the society. When seen from this perspective there should be equal opportunity for both the non disabled individuals and the individuals who have some or the other disability.

DISABILITY: TYPES

Classified in terms of impairment the classification brings to fore prominently the Visual Impairment, Hearing Impairment and Loco-motor impairment, which are being briefly discussed as follows:

Visual Impairment (VI): This characteristically has the key problem which is pertaining to blindness It involves the affliction of an individual from any of the following: entire absence of vision; or visual perspicacity not over and above 6/60 or 20/200 in the improved eye with acceptable lenses; otherwise in an inadequacy of the grounds of vision subtending an angle of 20 degrees or of an inferior quality and **Low Vision** (Visual functioning disability in an individual, even after the treatment or typical refractive correction).

Hearing Impairment (HI) - Persons with hearing impairment do not hear/ understand sound better, even with amplified speech. Included in this category are people having hearing loss of more than 60 decibels in the better ear (profound impairment) in the conversational range of frequency or total loss of hearing in both ears.

Loco-motor Impairment- In this kind of impairment, joints, muscles and the bones are affected. There is a noteworthy limitation in the limbs and consequently in the movement of an individual. This problem is significantly present in persons with cerebral palsy.

EPIDEMIOLOGY

Studies suggest that the very low rates of disability being picked up by censuses may correspond to only people with the most severe disabilities. (Group on Disability Statistics October, 2006)**.** An estimated 10% of the world's population experiences some form of disability or impairment (WHO 2006-2011)**.** There are 2.68 crores persons with disabilities in India who constitute 2.13

per cent of the total population.(The Associated Chambers of Commerce and Industry of India (ASSOCHAM), 2005).

Visual disability was found to be the most important single preventable disability (56%) as compared to other increasing disabilities like geriatric problems, particularly Hearing, speech and physical impairments.

Healthy life expectancy at birth in India is 53.30 and 53.60 for males and females respectively. As a part of this honorable legacy, an "epidemic of survival" is leading to substantial increase in the number of people live with disabilities *(Donald, 2002).*

The prevalence of persons with disabilities in European and North American countries has been around 10 to 15% of total population even in 1980s and early 90s. These figures may have become higher (around 20%) in recent years due to population aging and increase of disability awareness in these countries *(Hisao, 2004).*

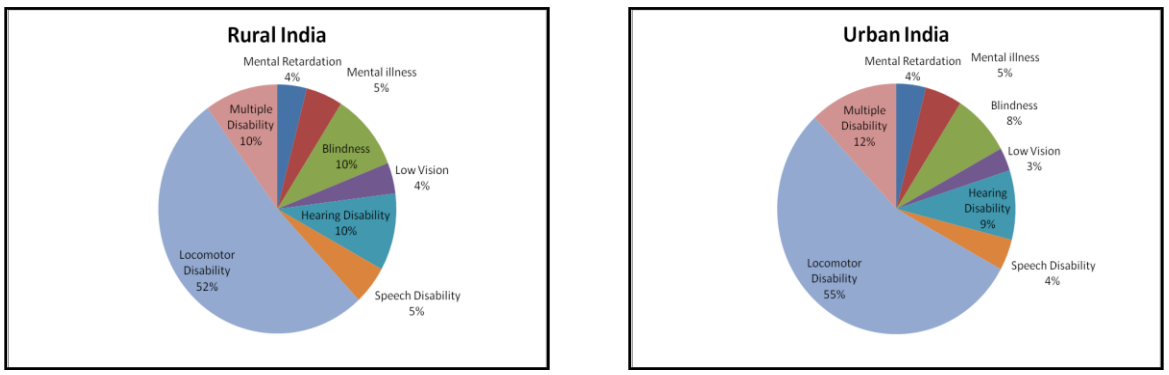


Fig. 1.1: Type of Disability according to Locale (NSSO, 2001)

Among the various disabilities it is the intellectual disability which has attracted the attention of psychologists most significantly, Genetics of disorders associated with intellectual disability such as primary microcephaly and fragile X syndrome trisomy of chromosome 21 have received research attention. Data

from developed countries and some recent studies in developing countries (Brazil, Ecuador, India, Nicaragua, Vietnam, and Zambia) suggest that an estimate of 10-12 percent is not unreasonable. *World Bank Report, (2006) (Girimaji SC, 2010).*

Since the present research is focusing only on one form of loco motor disability i.e. Cerebral Palsy, the discussion on Cerebral Palsy is imperative.

CEREBRAL PALSY: THE CONCEPT

"Cerebral palsy (CP) is an umbrella term encompassing a group of non-progressive, non-contagious motor conditions that cause physical disability in human development, chiefly in the various areas of body movement."

According to Cerebral Palsy Association (UCPA): "Cerebral Palsy (CP) is the general term applied to a group of permanently disabling symptoms resulting from damage to the developing brain that may occur before, during or after birth and that results in loss or impairment of control over voluntary muscles"(Goldenson, 1978).

Beukelman and Mirenda (1999): The word cerebral palsy is made of two words Cerebral - "of the brain" and Palsy - "lack of muscle control". So, cerebral palsy refers to "permanent disorders of the development of movement and posture causing activity limitation which attributed to non-progressive disturbances that occurred in the developing fetal or infant brain (PWD Act 1995)"

William John Little, FRCS in 1861 discovered the thought of Cerebral Palsy in Lancet published a number of his lectures, "Hospital for the Cure of Deformities: Course of Lectures on the Deformities of the Human Frame," in which he described spastic

deformities. His description led to the appellation, "**Little's Disease**," for what we now know as **cerebral palsy**.

For a child with CP, the process of growth is marked with the child's inability to perform complex activities. When the child grows, the consequences of the impairment of the brain are likely to be worse if the child is not given external help. However, this is true that despite the brain damage, the needs of a child and his willpower to function and interact are always present.

When there is a lesion in brain it interferes with the motor functions and leads to spasticity. If there are more passive movements in his treatment then the treatment is unlikely to bring any change in the brain function and its plasticity. Therefore, active engagement of the child is necessary for the treatment to bring in significant change. Also, the family condition and environment plays a vital role in the management of a child with cerebral palsy, hence effective family interventions are also needed (Hinchcliffe, 2007).

The situation where malfunctioning of motor control exists, there are possibilities of either of the combinations given as follows: gentle/mild, mediocre/moderate, and finally harsh/ severe.

Spastic individuals might undergo agitated tonicity due to disproportionate tensions in muscles and contractures in an unusual position. They typically tilt their head on one side, and then if having the knack they walk, with the help of a scissors gait in which knees are joint but feet are apart. When there is a lesion in the motor cortex region, it leads to Spasticity. People having ***Athetoid*** tremor's are categorized by uncontrolled hands or feet movements; both frequently go together with

incomprehensible/incoherent vocalizations with faulty hearing. Athetosis occurs due to the lesion in the area of basal ganglia. ***Ataxic*** individuals have uneasiness in balancing, as well as, have damaged perception of depth. Such people walk along with a staggering gait, and they often get the wrong idea about the distances. The ataxic form is due to a fixed cerebral lesion (Goldenson, 1978).

Sigmund Freud stresses that "Cerebral palsy is not the result of complicated procedure of birthing or any prenatal complicated-ness. Cerebral palsy is the consequence of few injuries in the brain during pregnancy and predisposition for a complicated delivery.

CLASSIFICATION OF CEREBRAL PALSY

- Categorization of Cerebral Palsy depends upon the nature of movement disorder or the level of limbs affected. In all there are **5 types of limb included**, which are as follows (Saunders, 1993)
- ***Quadriplegia*** - All four limbs are included.
- ***Diplegia*** - All four limbs are included but in comparison to arms both the legs get sternly influenced.
- ***Hemiplegia*** - One part of the body is affected; the arms are usually involved at a greater extent in comparison to legs.
- ***Triplegia*** – Three limbs are involved usually both arms and a leg.
- ***Monoplegia*** - Only single limb is influenced, mainly any one arm.

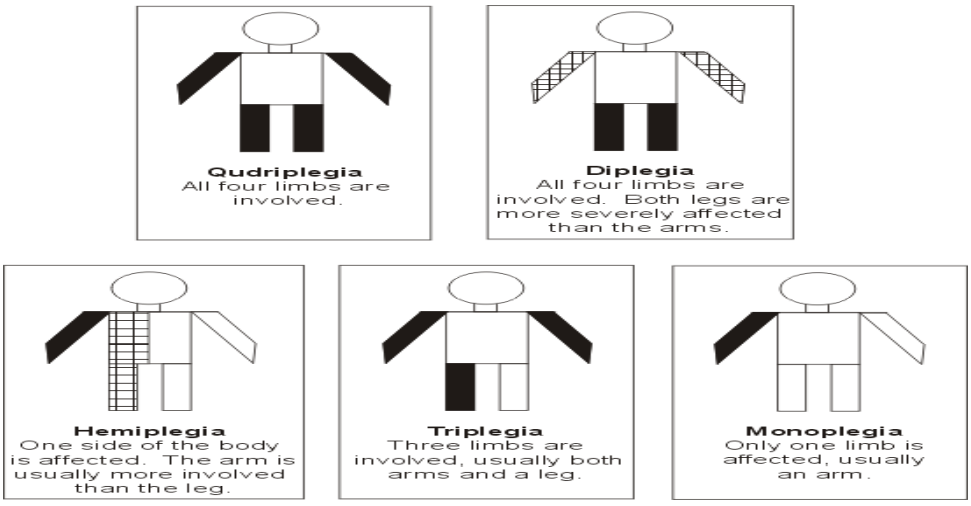


Fig. 1.2: Classification of Cerebral Palsy

- Under the movement disorder there are **four types of cerebral palsy** classified. The position of the injury in the brain decides how the movement will get affect. The four types are given as follows:

    1. Spastic cerebral palsy
    2. Choreo-Athetoid cerebral palsy
    3. Ataxic cerebral palsy
    4. Mixed-type cerebral palsy

1. **Spastic - Cerebral palsy-** Spastic Cerebral Palsy is caused due to the lesion in motor cortex area and is mainly the common problem. Spastic muscles are stiff and rigid resulting in limiting the movements of an individual with Cerebral Palsy. Usually, the working of the muscles is in pair and has two groups: as soon as one group gets constricted the other group gets relaxed at the same time, to permit liberated movements in the preferred way. Spasticity may possibly be gentle or mild but may affect some movements or the entire body depending on the severity.

2. **Choreo - Athetoid cerebral palsy-** Choreo-Athetoid Cerebral Palsy occurs due to the lesion in the area of basal ganglia or cerebellum. It leads to complications in controlling, as well as, coordinating the movement. Such children have uncontrollable movements which usually cease during sleep. Besides this they also face difficulty with the abilities that need coordination in movements viz. in speaking, grasping the object in a smooth way. Few terms used to explain these uncontrollable movements are as follows:-
   - Athetosis- movements are both low and writhing, (predominantly in the hands and face).
   - Ataxia- shaky walking and problem in balancing. Cerebellum is the chief point for the balance in the brain and damage to that part results in Ataxia.
   - Chorea- movements of the heads, arms, or the legs become erratic.
   - Dystonia- limbs and the trunks have the twisted movements.

3. **Ataxic cerebral palsy-** Ataxia is caused due to the damage of cerebellum. Ataxic cerebral palsy is not very commonly found type of cerebral palsy. Only 10% cases of cerebral palsy are found to be Ataxic. Few people have hypotonia as well as the trembles. Motor skills get affected because of this problem. For example: writing, typing or the sense of balancing, while walking, etc. (Fisher)

To keep her balance the child with ataxia walks bent forward with feet wide apart. She takes irregular steps, like a sailor on a rough sea or someone who is drunk.

Figure 1.3: Ataxic

4. **Mixed-type cerebral palsy -** When the part of the brain affects both the muscles tone and the controlled movement, it is diagnosed as "Mixed - Type CP". Typically the spasticity is

very much apparent. The uncontrollable movements increase with the development of the child (A guide to Cerebral Palsy) (Fox, 2001).

CAUSES OF CEREBRAL PALSY

Essentially, if there is any injury or harm to the brain whether inherent or while development or growth, may lead to cerebral palsy. (Saunders,1993).

Table-1.2: Causes of Cerebral Palsy

RENATAL	ATAL	POSTNATAL
1. ANOXIA: due to some problem with the umblical cord. 2. MATERNAL INFECTION: due to a viral or infectious agent such as rubella, toxoplasmosis, herpes simplex. 3. METABOLIC DISEASE: diabetes,heart condition, hyperthyroidism, severe asthma. 4. RH factor: RH sensititization- in compatability in blood groups of parents. **5.** If mother gets infected or injured then it directly affects the child. Moreover diseases like Jaundice can affect the child. **6.** A lot of exposure to radiation during frequent X-rays then also affects the growth of the child.	1. ANOXIA: Due to some obstruction involving the cord. 2. ASPHYXIA: Resulting from a mechanical respiratory obstruction. 3. ANALGESICS:- Administering of drugs affecting the respiratory center of the infants. 4. TRAUMA:- Any injury to the baby's head during labor, hemorrhage, forceps application, poor position of the infants. 5. PRESSURE CHANGES:- Too fast a delivery, also slow a delivery, caesarean section. 6. PREMATURITY:- complications at birth, respiratory distress.	1. TRAUMA: damage to the head by fractures or wounds. 2. INFECTIONS: childhood fevers, meningitis, encephalitis, brain abscess. 3. VASCULAR PROBLEMS :- viz. hemorrhage, thrombosis. 4. ANOXIA:- strangulation, carbon monoxide poisoning 5. NEOPLASMS:- tumors, cysts, hydrocephalus.

SIGNS AND SYMPTOMS OF CEREBRAL PALSY

Cerebral Palsy is a concept which explains a wide range of motor disabilities not developing or progressing any further. This problem occurs when the brain gets damaged before or after

birth. Estimation for the occurrence of cerebral palsy at the school age is every second child out of every 1000 live births in country. Symptoms can be visible when the child is not even 2 years old and often symptoms can be visible when the child is 3 months old. Parents might observe that the child takes a long time to do things, and the problems of delay in milestones achievement are evident.

The major symptoms are:

- Hands, feet or legs, etc. having irregular movement and shivers during stressful events which are likely to get worse at jerks or twists etc.
- Wobbly gait
- Failure of synchronization
- Flabby muscles as well as the joints in motion to a large extent, specifically when relaxing.
- Low level of intelligence and slow learning
- Difficulty in speaking (dysarthria)
- Difficulty of listening and seeing
- Paroxysms
- Aches, particularly in adults
- Having trouble in sucking, swallowing, chewing and eating.
- Augmented salivation
- Nausea and constipation
- Delayed Milestones of Development
- Incontinence (Kaneshiro, Bethanne et al, 2013).

TREATMENT & MANAGEMENT OF CEREBRAL PALSY

The management of patients with cerebral palsy must be individualized based on the child's clinical presentation and requires a multidisciplinary approach. Rehabilitation is a

"comprehensive intervention strategy designed to facilitate adaptation and participation in an increasing number and variety of settings in a particular society and culture." Neurologists and rehabilitation medicine specialists (physiatrists) play significant roles in the management of anti spasticity medications. The physician's responsibility is to closely supervise and manage the multiple clinical complications associated with cerebral palsy.

Treatment requires a team approach, including Primary care doctor, Dentist (dental check-ups are recommended around every 6 months), Social worker, Nurses, Occupational, physical, and speech therapists.

Physiotherapy programs are designed to encourage the patient to build a strength base for improved gait and volitional movement, together with stretching programs to limit contractures. Many experts believe that life-long physiotherapy is crucial to maintain muscle tone, bone structure, and prevent dislocation of the joints. **Occupational therapy** provides a help to the adults, as well as, children to make best use of their capability. Counseling of the parents is an important part of the therapeutic treatment for capacity building of the parents (Steultjens, 2004)**. Speech therapy** helps in controlling and managing the mouth's muscles and the jaws, so that communication can be improved. Besides affecting the arms and the legs movement, cerebral palsy can also affect the movement of the face, head and mouth. This impairment can result in difficulty to breathe; speak clearly; even to nibble, chew or in swallowing the food (Pennington, 2004). **Medical Treatment** is the most sought treatment for Cerebral Palsy. Injections like Botulinum toxin A (Botox) are injected into muscles that are either convulsive

or having contractures. The basic goal is to alleviate the disability, as well as, to reduce the pain due to improper muscle contractions (Steultjens, Dekker, Bouter, JCM, Lambregts, 2004). Anticonvulsants are used to minimize the seizures (Heinen, 2010).

SELF CARE & COMMUNITY CARE

Self-care is an activity performed by the children to take care of themselves. Activities which involve self-care include taking bath, dressing up, etc. These self care activities can be difficult to perform for children depending upon their upper limb's use.[Jenks, Moor, Lieshout, Maathuis, Keus, Gorter (2007)].Due to the use of the hands in most of the activities of self-care it is important to facilitate the sensory and the motor movements. The degree of the impairment in hands is depended upon the position as well as the amount of the damage in the brain. Often due to Cerebral Palsy induced sensory impairments, it becomes difficult to perform daily activities like brushing the teeth, dressing etc.

Motor impairments are more significant in comparison to sensory impairments. One of the major problems is finger numbness. It is the problem where manipulating small objects is difficult, for example tying shoelaces. These children also have oral sensory disturbance for instance, there is too much sensitivity in the mouth or there is no sensitivity in the mouth.

TYPICAL PROBLEMS OF PERSONS WITH CEREBRAL PALSY

According to Murphy (1982), due to disability there are extra demands and the challenges imposed on the family system. In fact maximum of these demands are even long lasting. Challenges faced by the families are contingent upon certain factors like type of the

disability, age or the family's structure etc. Other factors like demands concerning medication, education, fooding, required tools and equipments for the disablers, modes of transportation, etc. also complicate the issues. The core of these factors is the economic conditions. At times these problems are compensated by insurance companies or the funds raised publically. But problem arises when the families fail to certify the eligibility of their member to take the concerned services. In case, if the family provides a proper evidence and certificate for the disability only then they can get the services Sloper and Turner (1992).

While talking about the challenged, one cannot ignore their basic needs and problems they confront in their day to day life. Few of the basic need of such people are their fooding, clothing, bathing, cooking, eating, going to washroom, etc. Moreover, there are problems in their schooling, livelihood, financial management, management of their home, marriage and having a family. Further, their personality development, security (especially in case of girls), social relationships, handling relationship conflicts etc. are other problems which the disabled people face. Usually challenged people remain as unemployed member of the family because of the lack of opportunities. In many cases it has also been seen that presence of other members of the family is necessary to take care the disabled person which in turn makes them also unemployed. Finally, the pessimistic and negative attitude of the society can also be very detrimental for their being (People with Disabilities in Rural India, 2009).

EMPOWERING THE CHALLENGED

For helping the disabled people to become an active member of the nation's growth, the development of the disabled people becomes a priority. Taking this into cognizance, government of India has introduced various Acts and also includes it in other programs and five year plan for the disabled people, which are as follows:

- Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.
- National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999.
- Rehabilitation Council of India Act, 1992.
- UN Convention on the Rights of Persons with Disabilities. (DEOC, 2009).

The Annual Report of Ministry of Rural Development covers details on the coverage of Disability Sector. 'All District Rural Development Agencies (DRDAs) were instructed to follow the Guidelines of the Poverty Alleviation Programmes in Implementation of "Persons with Disabilities Act, 1995". Follow up action was taken on the Provision of Reservation of 3% for Disabled in the major Poverty Alleviation Programs (implemented by Ministry of Rural Development) which include the SGSY, SGRY, IAY.' Director (Monitoring) is designated as the nodal officer in the Ministry of Rural Development for matters relating to the "Persons with Disabilities Act, 1995

INCLUSION OF DISABILITY IN VARIOUS PROGRAMMES OF SOME RELEVANT MINISTRIES:

Following are the schemes and policies made for the challenged to address their poverty, livelihood, education and social security needs:

a. National Rural Employment Guarantee Act (NREGA)
b. Sampoorna Grameen Rozgar Yojana (SGRY)
c. Swarnjayanti Gram Swarozgar Yojana (SGSY)
d. Indira Awaas Yojana (IAY)
e. National Social Assistance Programme (NSAP)
f. National Old Age Pension Scheme (NOAPS),
g. National Family Benefit Scheme (NFBS), and
h. National Maternity Benefit Scheme (NMBS).
i. Integrated Child Development Services (ICDS)
j. Sarva Shiksha Abhiyan (SSA)
k. National Rural Health Mission (NRHM)

REHABILITATION SERVICES

The Ministry of Social Justice and Empowerment is the Ministry that protects the intrests and rights of the disabled. Several National Institutes under the Ministry of Social Justice and Empowerment are as follows:

- National Institute for the Visually Handicapped, Dehradun.
- National Institute for the Hearing Handicapped, Mumbai.
- National Institute for the Mentally Handicapped, Secunderabad.

- National Institute for the Orthopedically Handicapped.
- Kolkata, National Institute of Rehabilitation Training & Research, Cuttack.
- Institute for the Physically Handicapped, New Delhi.
- National Institute for the Empowerment of Persons with Multiple Disability, Chennai. and
- Indian Spinal Injury Centre, New Delhi.

Some of these institutions have Community Based Rehabilitation (CBR) and plans for people with disabilities in rural areas.

Ministry with State Government's dynamic support smoothens the progress of setting up **District Disability Rehabilitation Centers** (DDRCs) to give treatment facilities to the disabled persons. Between 1999-2000, total 199 DDRCs have been approved, 148 have been set up and have also begun to function. During 2006-07, another 50 DDRCs have got approved. Grants have been given to 12 DDRCs out of 50 DDRCs. Besides this, to render both precautionary, as well as, promotional features of treatment to the disabled persons, the Ministry has set five Composite Regional Centers at Srinagar, Sundernagar (Himachal Pradesh), Lucknow, Bhopal and Guwahati.

FIVE YEAR PLANS

In **Eleventh Five Year Plan,** a very precise assurance is made to develop a Disability Medical Rehabilitation. It emphasizes training for human resources and Health Care Delivery System of medical rehabilitation at medical colleges as well as districts. The focus is:

- To grow and expand the departments of Physical Medicines and Rehabilitation (PMR) in the nation which may act as Model Centers.
- To establish minimum one PMR Department in each state, altogether at least in 30 Medical Colleges or in the Teaching Institutes. In addition to this, each and every department must accept districts, Community Health Centers (CHCs) and Primary Health Centers (PHCs) for the growth of Medical Rehabilitation Services.
- To give professional training for medical rehabilitation, thus, offering services of rehabilitation at secondary as well as tertiary level.
- To launch guidance and teaching programmes on the prevention for disability, recognition, and early intervention at the undergraduate, as well as at the postgraduate level.
- To grant Services of Rehabilitations in Medical Hospitals and also develop the various policies for care.

Accessibility and inclusion of Persons with Disability remains a challenge. While the world has taken giant steps towards inclusion, India still has a lot of work to do towards inclusion and mainstreaming the Persons with Disabilities. At this juncture, it becomes imperative to briefly discuss the concept of inclusion.

INCLUSION

'Inclusion', is being used by people with disabilities and other disability rights advocates with the idea that all people should freely, openly and without sympathy accommodate any person with any kind of disability, physical, mental or intellectual, without restrictions or limitations of any kind. "The true essence of

inclusion is based on the premise that all individuals with disabilities have a right to be included in naturally occurring settings and activities with their neighborhood peers, siblings, and friends" (Erwin, (1993).

Inaccessibility is a major barrier for full participation of persons with disabilities which calls for the need of inclusion. Majority of people with disabilities are confined to their homes or are excluded because they are unable to have access to any of the public places, transportation or services. Bus stands and railway stations are almost impossible to access for the PWDs. Visiting public places like markets and shop is still avoided by persons with disability. Even basic services like public toilets are not friendly for them. Community Based Rehabilitation initiatives which always adopts a rehabilitation approach have also made room for rights-based perspectives and Inclusive development. This challenge needs an urgent government action. Unfortunate state of art in India is the lack of understanding and indifference towards disability.

Among the various kinds of inclusion, it is Inclusive Education which has obtained maximum attention of policy makers in India particularly in reference to implementation for mainstreaming of CWDs in regular schools.

Inclusion is somewhat more values-oriented than integration. Supporters of **Inclusive Education** use the term to refer to the commitment to educate each child, to the maximum extent in the school. It involves bringing the support services to the child and requires that the child will benefit from being in the class rather than having to keep up with the other students (Rogers, 1993).

In Indian context, a disabled friendly attitude is often seen as comparison laden on charity or pity with family being seen as the single support. Paradoxically, in the west, relative lack of family or community support have encouraged the disabled activists towards ideas of independent living. The fact of exclusion of the disabled from certain spheres of life in the Indian context is supported by surveys, but community support is relatively easier to come by (Das and Adlakha, 2001).

STATE OF ART

In general people tend to hold a rather fatalistic perspective towards the disabled in the rural areas. It is believed that it is one's karma, or the destiny which leads one to this state of disability. So they are as a result subjected to social rejection and exclusion. Besides this, another mindset prevails that if an individual is disabled then he is merely a burden in the family and cannot do anything and so his family needs sympathy, guidance and assistance. There are increased level of family discord in such families. The parents of such children have very disturbed marital life and social relationships. There is a lot of financial pressure, depression, social discrimination and social exclusion leading to a lot of frictions and conflicts in the families (Dalal & Pande, 1988). Gupta (2004) also gives the concept of 'family resilience' in this context (Gupta. A, 2004).

RURAL SCENARIO: GRASSROOT REALITIES

The occupation of people living in Indian villages is mainly agriculture, which is not only seasonal but also adds a lot of uncertainty, and economic insecurity. This predisposes them to be trapped in the vicious cycle of poverty. In addition, the uncontrolled

rise in population coupled with dwindling cottage and village industries and uncertain whether condition has further aggravated the problem. The state of art would be clear with the findings of NSSO survey (2006) and National Health report (2010).

MAJOR HIGHLIGHTS OF NSSO SURVEY, 2006 :

- 74.68% people of country's total population reside in rural areas. Population below poverty line is 26.1% in India. Whereas in UTTAR PRADESH 31.15% people live below poverty line.
- 91.4% of total STs 79.8% of total OBC belong to rural areas. All India average monthly spending by rural STs was the lowest at Rs. 426.19 followed by rural SCs at Rs. 474.72 OBC at Rs. 556.72 and others at Rs.585.31. In rural India, 64.3% of the population continues to be dependent on agriculture where 29.9% work as agriculture labor. It seems that dependency of agriculture is larger than any other industry and this is the root cause of poverty.
- There is growing disparity between agriculture and non agriculture income largely due to large proportion of people dependent on agriculture, the average size of holding decreasing annually and the term of trades between agriculture industries are largely unfavorable for farmers.
- With reference to literacy the picture is dismal, although the literacy rate in the country had increased from 18.33% in 1951 to 65.38% on 2001 but in rural areas it is quite poor from the urban areas as evident in the below table:

Table-1.3: Rural Urban Gap of literacy (literacy census, 2001)

Area	**%**	**Male**	**Female**
All areas	65.8%	75.3%	(53.7%)
Rural Areas	59.21%	71.18%	46.58%
Urban Areas	80.06%	86.42%	72.99%

MAJOR HIGHLIGHTS OF NATIONAL HEALTH REPORT, 2010

The update of national health policy, the national health report 2010, brings to fore the following facts:

- Nutrition, Access to safe drinking water and sanitation, and Education are the three most important proximate determinants of health status that have an impact on both infectious disease and vital health statistics. All these three are closely related to poverty and marginalization. In addition, marginalization and discrimination on account of gender and caste are social determinants themselves. It is therefore not surprising that the poor performing states are those with the highest levels of poverty and the highest levels of malnutrition, among children and adult women.
- Malnutrition and Anaemia: of great concern is the persistent level of malnutrition with over 40% of children and 36% of adults women classified as undernourished. The reasons for such high levels of malnutrition and anaemia include poverty, gender inequity, and recurrent illness. However, for more serious attention, we need to look into the health parameters

of India, its states, and its marginalization section which give an insight into development in general.

Unfortunately, health has been a much ignored sector. Not only the state of art and epidemiology is poor but the services are also poor. Therefore, a brief discussion on health and mental health is imperative. Such a state of health indicators in the rural sector motivated the researcher to address the health issues of the PWDs. Hence, the concept of health and mental health need to be addressed at this juncture.

Table-1.4: Health Indicators, National Health Report, 2010

Selected Health Indicators (National Health Report 2010)				
Parameters	***1951***	***1981***	***1991***	***Current levels***
Crude Birth (CBR) (per 1000 population)	40.8		29.5	23.5
Crude Death Rate (CDR) (per 1000 population)	25.1	12.5	9.8	7.5
Total Fertility Rate (TFR) (Per women)	6.0	4.5	3.6	2.9
Maternal Mortality Rate (MMR)	NA	NA	437	301
Infant Mortality Rate (IMR) (per 1000 lives birth)	146	110	80	57
Child (0-4) Mortality Rate (per 1000 children)	57.3	41.2	26.5	17.3
Life experience at birth				
Male	37.2	55.4	59.0	62.3
Female	36.2	55.7	59.7	63.9

HEALTH

To a psychologist, health is a normal functioning of mind, to a physician it is principally the normal functioning of the body; people's attitude to health, their idea about the causes of illness, and the relationship between attitude and behavior portrays different meaning of health in their mind. To many individuals, it merely means freedom from poor health. (Nandy, 1969) Health systems and practices in all societies are based on certain shared belief about the world, self and human existence. These cultural beliefs provide the necessary framework for defining health, understanding the causes of illness, and deciding the modes of treatment (Dalal & Singh, 2001).

According to Verma & Kaur (2000) "Health refers to the full and harmonious functioning to the total personality, which implies the presence of positive health that is physical, psychological, social and spiritual well being; and the absence of negative health; that is the absence ill being." On one hand where health is defined as the general condition of a person in all aspects and a level of functional and metabolic efficiency of a human being, on the other hand, health is also defined as the ability to live effectively in one's environment.

Rural development, especially the health status of India's rural population is a cause for concern. Health system requires a large paradigm shift from the current 'biomedical model' to a 'socio-cultural model', which should bridge the gaps and improve rural health, is the current need (Sinha, 1990). A revised National Policy addressing the prevailing inequalities, and working towards promoting a long term perspective plan, mainly for rural health, is

imperative, which incorporates mental health also. At this point it is essential and briefly address mental health.

MENTAL HEALTH

Mental Health is defined as a state of well being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (WHO). Nevertheless, in keeping with the WHO definition, mental health professionals are at least unanimous that mental health is not the mere absence of mental illness (Eichler & Parron, 1987; Nagaraja, 1983).

Various psychologists have given certain characteristics of a mentally healthy person. Henry (1953) defined it as successful adaptation of the normal stressful situation. **Jahoda (1955)** took a little broader view to explain mental health. According to him a mentally healthy person possess following characteristics:

- The person displays active adjustments or attempts at mastery of his environment in contrast to lack of adjustment or indiscriminate adjustment through passive acceptance of social conditions.
- The person manifests unity of personality – the maintenance of a stable integration which remains intact in spite of the flexibility of behavior which derives from active adjustments.
- The person perceives the world and himself correctly; independent of his personal needs.

CHARACTERISTICS OF MENTAL HEALTH (WHO, 2001)

WHO (2001) defines the characteristics of mental health as follows: (a) **The ability to enjoy life** (b) **Resilience** (c) **Balance** (d) **Flexibility** (e) **Self actualization.** Mental health has often been interchangeably used with the concept of emotional well being indicates mental health. According to Sharma (1997) a person's well being depends upon positive and negative affect that an individual feels from the environment and about himself.

Positive Well Being: it is an individual's feeling of his surroundings in a conducive way, providing him/her positive affectivity for the environment. He thinks the environment and himself as helpful, good, happy, and great feeling of accomplishment.

Negative Well Being- is the negative affective dimension that one feels about oneself. It is different from positive well being and includes a great syndrome of some negative factors and is known as distress also that one feels oneself as degraded and hopeless person.

Among the indicators of mental health, happiness and relationships figure out rather prominently. Relationships act as a stress buster. Since the present study takes up the relational world of the PWDs, hence relational world is being discussed briefly.

Self Other Relatedness

"The greatest of all sorrows is to feel alone, to feel unwanted, deprived of all affection."
-Mother Teresa

Nothing affects the human personality so much as the relationships. It is only in the context of others that our needs

can be met (Parrot, 1998). We need trust, support, affection, love and last but not the least is the sense of belongingness. According to **Josselson (1996) "Relatedness not only involves other people as object of desire, but it also serves as a context for the experience of the self."** Each one of us has two worlds within us- **internal and external.** The ways in which we relate to our external world will decide how we construe and relate with ourselves. So relationships become an important parameter of not only one's sustaining but one's well being also.

Laing (1990) states that **"The sense of identity requires the existence of another by whom one is known; and a conjunction of this other person's recognition of one's self with self recognition."** He stresses on the relationship of self with others. An integral sense of self is entirely dependent on the affirming relationship with the external world.

DIMENSIONS OF RELATEDNESS

Josselson (1996) states that there are eight primary ways in which the individual reaches to bridge the space between him and others to make connections as development proceeds, each way of connecting becomes more symbolic, less physical and spatial. These dimensions are as follows:

1. **Holding:** Holding is the first interpersonal experience and represents security and a basic trust that what is essential will be provided. We continue to need to be contained, bounded and grounded in order to grow.
2. **Attachment:** The propensity to attach to others, structures few of the most fundamental processes throughout life, including the painful vulnerability to lose that is part of our

human core. Throughout life, we continue to form attachments and those are often at the centre of our experience.

3. **Passionate Experience:** In the realm of passionate experience, others are objects to drive gratification. Contacting others through our drives is the mode of passionate relating: overcoming separateness through sexual union or its symbolic expression. The pleasure of touch and the possibilities of uniting in boundary-less bliss are powerful means of transcending space.
4. **Eye to eye Validation:** In eye to eye relating, we overcome space through the communication of eye contact, finding ourselves in the other's eyes, having the place in the other. In this, we connect by existing in and for someone else.
5. **Idealization and Identification:** After existing for a time in this external world, we begin to notice that some are bigger, stronger and more able to do things than we are ourselves. When we idealize and identify with others we reach up for them, try to climb through the distance that separates us, these are ways of expanding ourselves.
6. **Mutuality:** As a person grows, through childhood and the self matures and becomes aware of others, the child eventually discovers the possibility of engaging the self with others and is able to experience companionship, which is a form of mutuality.
7. **Embeddedness:** When we are embedded with others and are comfortable in our role, our place. It is not usually until adolescence that the concern with having a place in society becomes paramount.

8. **Tending and caring:** The developing person has been learning about taking care of others, offering the self to others needs, bridging the space through tending and caring.

Any given relationship may involve more than one of these dimensions, simultaneously or sequentially. **Josselson (1996)** describes the first four dimensions (holding, attachment, passionate experience and eye to eye validation) as Primary. They are present either from the beginning of life or shortly thereafter. The other four dimensions require cognitive maturation and may not develop until late childhood. Although each of the dimensions is present to at least some extent in every one's life, people often develop along particular relational pathways that highlight one or two relational themes of the internalized self object relations and self other relatedness.

REVIEW OF LITERATURE

This review of literature largely pertains to the socially excluded particularly Persons with Disabilities. An attempt is being made here to review the empirical studies done on such **economically and socially marginalized population,** particularly, the disabled. Fig. 1.5 shows the major variables across which the studies on the challenged have been reported.

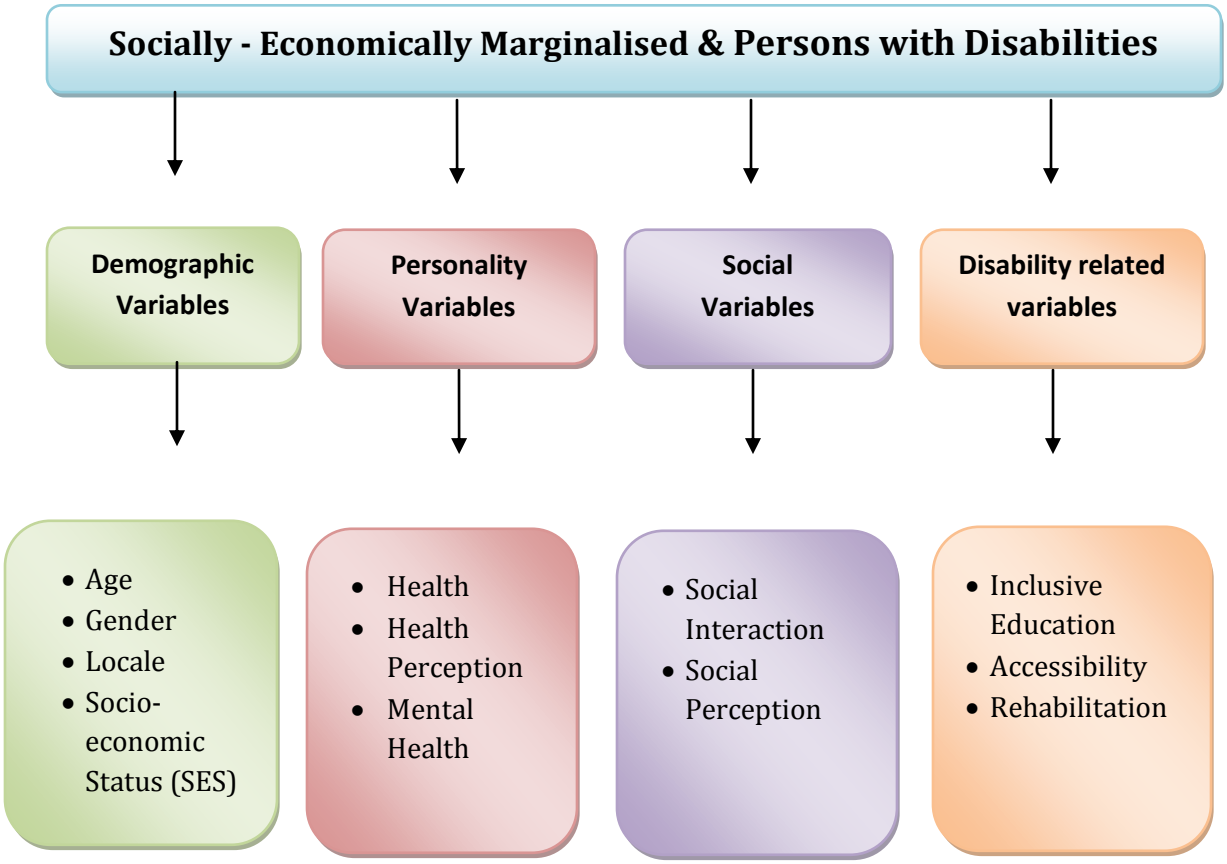


Fig. 1.5 : Ready Reckoner to Review of Literature

REVIEW UNFOLDS

1. DEMOGRAPHIC VARIABLES

* **Age and Disability**: With reference to age, the research review brings to fore, three major trends, firstly it focuses upon researches on specific age group i.e. children, adults and elderly. Secondly, it highlights comparison of different age group with reference to disability. Thirdly, the trends with reference to longevity and disability are highlighted.

Among the various cross sections of PWDs taken as sample for research, children and youth seem to have taken the front seat, thus, Newacheck (1989), Clerk (1990), Filmes (2008), take as their sample children and youth focusing on various issues like severity of chronic illness and health services in community (Newacheck, 1989,Ireys & Nelson,1992; Fiene & Taylor,1993; Malach & Segel, 1990), Community networks, Clerk (1990), transition goals (Mc Ginky and Fish, 1992), school enrollments , filmes(2008). Educational attainment and regularity of school going children was found very poor in children with disabilities (World Bank, 2007).

Another set of researches focus upon adolescent PWDs with reference to their adjustments, Lavigre,(1992), Wallander, (1998). On the similar note, Shemesh , (2002) explores depression and heath of adolescents with disability. Edwards (2002) advocates empowerment and mainstreaming of adolescents with disabilities. Grnky & Fish (1992) recommends examining the status of the young PWDs. Mitra & Sambamoorthi, (2006), analyzed the data of salary waged employees with reference to their disability. Mohapatra & Mohanty(2004), in their research on young people

with disability highlight how they get married at later age in comparison to rest of the population or remain unmarried and stay with parents.

The researches with elderly PWDs are somehow less in number. Manton (1989) contends elderly PWDs to be the largest number of PWDs which seems to be creating trend for dramatic increase in the future. Dwyer & Miller (1990) reported more chronic illness and physical impairment in the rural elderly. Sengupta (2002) explored the disclosures of physical impairments in elderly PWDs with reference to a comparison of South with North.

Another set of researches focus upon the status of PWDs at the margin of mainstream society (Ridll & Baron, 2001; Brounholtz, 2007). NSSO data shows a trend of decline of disability in 0-9 age group whereas paradoxically it shows an increase in the incidence of disability from 10-29 years. On a positive note, world Development report, 2007 suggests 5 areas of youth transition i.e. continuing to learn, starting to work, developing a healthy lifestyle, beginning a family and exercising citizenship.

Finally, a research taking both young and old people in understanding the concept of disability also reflects better comprehension and understanding in the young group (Hedland, 2000).

* **Gender and Disability:** Two trends of researches are visible with reference to gender in disability sector.
    1. Researches focusing only on women/men.
    2. Researches highlighting gender differences with reference to disability and related variables.

Among the researches done on the basis of gender, some researches tried to explore the status of women and men with disabilities. Women with disabilities were subject to significant domestic and sexual abuse, and situation is worse for mentally challenged women with other types of disabilities (Action Aid, AP, 2000). On similar lines, young disabled women were found at risk of sexual assault and exploitation, Mahapatra and Mohanty (2004). They also found vulnerable state of disabled women and girls for sexual abuse. Another study explores the gender gap in schooling and need for greater encouragement for girls Kalyanpur, (2008). On a macro level Mehrotra, (2004) highlights how women with disabilities in India face double discrimination due to prevalence of traditional gender roles and expectations. Infanticide of the disabled is widespread, with girl child at a higher risk. Medical, nutritional, educational, emotional, psychological, sexual, and recreational and employment needs of a disabled daughter are the last priorities of a family. Society needs to realize the immense potential in the strength of women with disabilities and their capabilities in taking the disability rights movement of the country forward (Broota, Sakshi, 1998). According to NSSO report work participation varies quite dramatically by the type of impairment, and young men with locomotor, hearing, low vision and speech impairments were more likely to be in employment, compared with those with severe visual or mental impairment, NSSO (2003).

Some researchers opted to study gender related dissimilarity in social behavior pattern which leads to effect women and men in a broader way. Menson (2000) contents that in comparison to men, disabled women are discriminated firstly because of their gender

and then disability becomes another reason for their discrimination. Another study done by National Commission for Women, Government of India (2013) states that the general attitude is still that a disabled woman has little hope of becoming a wife or a mother, or of getting a productive and rewarding job. Thus, the normal tendency among the laymen is to visualize the women with disabilities as a burden on her family, society – a dependant for the rest of her life. Singal & Jeffery (2009) mentioned that being married strongly increases a man's probability of being employed while it reduces that of a woman's and that surprisingly, education has a limited effect on the probability of being employed for women with disabilities (Singal & Jeffery, 2009).

* **Locale and Disability :** There are various concerns emerging as variables in terms of distribution of entitlements, services, supports etc. especially geographical locality i.e. rural in case of PWDs as much variability exist in rural than in urban area.

In context of disadvantages, isolation and exclusion of persons with disabilities (PWDs) of rural areas has been reported in a number of researches. Gething (1997), Baily(2002), Kulpers (2001), Donald (2004), Foy (1997), Freya(1993), Lezzoni, Kullen & O'Day(2006), Daley (2011), Ingstad & Whyte (2007), Saloojee (2007). further social and emotional support and poor services to rural population with disabilities they also face exclusion from mainstreaming, health services, Kupers (2001), Bushy (1994), Purtilo (1986), Bushy (1993), Hanstein (1994), Confidentially and Privacy, (Bourke 2003, Glendening 2003), also in respect of health care (Burnes 1990 Dana 1990), Green wood (1985), Offner (1992),

Thurston ,Meadows (2003), Elliott-Schimilt , Strong (1997), Ross (1990), Mental health has been found to be neglected and awareness for the same is far low as well,(OTA 1990) Some studies also focused on vulnerable and marginal groups in rural Sector (Loch 2008, Smit 2004, Rohledger 2009, Jarzynouskan & Shortt 2010).

With regard to accessibility, both physical, as well as, entitlements for PWDs is concerned various findings show remarkable differences between rural and urban groups, (OTA-1990, Steel, Spas off & Alexender 1985, Momthern 1998, Thurston 2003, Roserberg 2000, Duncan 1993, Jeffery and Singhal 2008).

* **Socio Economic Status and Disability:** Research on SES in disability sector primarily focus upon three major concepts closely linked to SES, these are: Income, Employment and Education. As education is being covered under Inclusive Education, Financial status in terms of poverty and employment are being discussed here:

* **Poverty and Disability –** Poverty is also a cause of disability. Poor often lack resources to prevent malnutrition and do not have access to adequate health, education etc) which plays an important role in preventing disability; Leymat, Annetal (2006) Peters 2008) Green 2006) Fukuda-Parr 2006). In South African content poverty is linked to past history where apartheid played major role, (Crais, 2002). Link between poverty and disability cannot be underplayed which should be acknowledged with integrating strategies of health policies; Guet, Brathen (2012). In developing countries, research related to disability is more

focused on the relation between disability and poverty; (Train & Loes 2010), Braithwaite & Mont 2009), Hoogeven 2005), Yeo & Moore (2003). Cases illustrate PWDs who live in poor areas, experience house problems, barriers and suffering (Earmer, 2001).

No clear estimates of the number of persons with disabilities and stigma surrounding disability are very clearly available. Many individuals with severe impairments, mainly women and rural poor persons with disabilities are excluded from census and surveys, (Jeffery & Singal, 2008). Poverty leads to homelessness especially among the urban destitute and disabled; this abandonment with social stigma perpetuates the invisibility and isolation of many persons with disabilities; (Jeffery & Singal, 2008); UNNATI & Handicap International, 2004); World Bank, 2007).

* **Employment and Disability-** Assessment for good employment for PWDs is low even in case of locomotor disability (Swabhiman, 2004). Variation in attitudes exists over the possibility of employment for PWDs. It is observed and discussed that people with locomotor, vision, speech and hearing disabilities can be successfully employed but people with mental disabilities face greater negative attitude; (Erb and Harries-White Opcit 2002). State denies the correlation between disability and poverty which creates a vicious cycle in employment opportunity for PWDs. However, since the opportunity to earn is much less for the PWDs and their expenses are more, it results into families of PWD being poorer than others. Majority of PWDs are unable to earn their livelihood (UNESCO, 1998). Large numbers of PWDs of working age are unemployed in comparison to industrialized

country 50% ratio. PWDs employment probability of PWDs attributed to characteristics from discrimination in employment opportunities (Mitra & Sambamoorthi, 2008). Most training programs do not match the demand of the service sector leaving most persons with disabilities unequipped to avail the highly-paid jobs in this transitional phase of the Indian economy (ILO 2003). Huge population of the rural disabled is deprived of access to technology and jobs that involve its application (Sridhar, 2003). The percentage of employees with disabilities in public sector companies is 0.54, while in private companies only 0.28 percent employees were disabled (Abidi, 1999).

3. PERSONALITY VARIABLES

Health and Disability: The challenged people face certain health hazards due to their challenges of being unable to fully exercise or utilize all parts of their body. Also, their challenge pre dispose them to certain health problems, besides the lack of understanding of one's problems add to greater health risks. Review of the health issues of the PWDs revolves around three major areas of health, which are: access to health, awareness to health and health problems.

PWDs residing in the rural areas do not have good access to health care facilities; face numerous obstacles which include insufficient referrals, lack of transportation, remoteness of secondary and tertiary facilities, and lack of financial resource and absence of current information on disability. Also, persons with physical impairment often lack opportunities to engage in preventive health care activities (Offner, 1992; Dejong, Batavia &

Griss, 1989). Moreover, Pope(1992) also mentions that people with disabilities often experience lack of access to health services and medical care and are considered to be at increased risk for secondary condition, such as musculoskeletal or mental health problems consequent to the primary disabling conditions(Healthy People, 2010). Rehabilitation services and access is very poor in most developing countries, (Poulis, 2007; Lang and Upah, 2008; Mji, 2009). These researchers also contend that despite of a higher proportion of disabilities among rural children living in poverty as compared to their urban counterparts, poor rural children experience even greater problems related to access to pediatric care. However, on equalizing the opportunities for PWDs, some countries have tried to develop strategies to address disability viz (South Africa Integrated National Disability –SAIND (Whitepaper, 1997).

In India, there are no clear estimates of the number of persons with disabilities. Concerns persist that, given the stigma surrounding disability, many individuals with severe impairments, mainly women and rural disabled, are excluded from census and surveys (Jeffery & Singal, 2008).

Students with disability report health problems of breathing, bronchitis, asthma, allergies and vision, whereas few reports of depression, anxiety, mood or personality disorder, digestion and cardiac problems also (Bourke, 2013). There is evidence that significant proportion of PWDs have a greater than average risk of cardio-vascular diseases and often PWDs are incapable of performing lower limb exercise tests widely used in the diagnosis of the coronary heart diseases (Cooper; Rimmer Braddock, 1996).

Many studies related to disability among the elderly have confirmed that increasing age tend to be associated with increased risk of disability and that multiple conditions incrementally increase the risk for disability (Srinivasan, 2008; Joshi, 2013).

* **Health Perceptions and Disability:** One's health is determined by how one feels about it and in large scenario how others address his challenge/ health problem with special reference to PWDs.

  Three major categories of researches emerge in this context, which are as follows:

  - Those pertaining to the perception of the disability and disabled
  - Perception about disability in the society
  - Effects of social stigma on persons with disabilities.

Perceptions for disability have been explored by Bourke (1996), Mulvaney (2000), Shakespeare (2005), Thomas (2007), Thomas (2007), Brown et al (2009). Negative semantics in terms of perception were obtained by rural young people in Australia wherein the most common perceived meaning of disability were " Can't do particular things", "physical or mental limitations", "not normal", "can't function like normal people", "disadvantaged" etc. (Bourke, 1996). In addition, disability in the Indian context is often understood as a 'lack' or 'deficit' as well as a 'difference' (GHAI, 2009).

Having a child with disabilities not only affects the parents, but also the siblings and the relationships among the family members (Gupta & Singhal, 2004). Another study states that often additional stress is created due to marital conflicts associated with

rearing the handicapped child, extra financial burdens, fatigue and loss of leisure time due to care-taking responsibility (Mc Andrew, 1976). Though some, surveys have been conducted in India with respect to the mentally retarded (Pandey & Advani, 1995), however, Rights-based model of disability built on the insights of the social model to promote creation of communities which accept diversities and differences, and have a non-discriminating environment in terms of inclusion of PWDs in all aspects of life is a more positive ray of hope (WDR, 2007, Disability in India). Besides, limited resources and negative societal attitudes to sexuality also have been found to add to the stress.

Often parents who want to address the sexuality concerns of their growing or adult children with disabilities do not have any services that they can access (Puri, 2010).

Stigma has been found to be associated with disability. Stigmas, negative labels, social exclusion and poor treatment of PWDs lead to poorer mental health (Mulvaney, 2000); Shakespeare, 2005; Thomas, 2007; Brown, 2009; Frost, 2011; Mc Phedran, 2012). Inequity and stigmatization seem to be a normal phenomenon in the management of persons with disabilities. Such perceptions of the disabled by the non-disabled have the dual effect of not only justifying the complete marginalization and disempowerment of the whole population group but also leads to the internalization of such negative stereotypes in the persons with disabilities." (Addlakha, 2007). Furthermore, the World Disability Report also states that disabilities that are more visible (physical disabilities or mental disabilities) are more stigmatized than the

invisible disabilities (hearing disabilities), thus reflecting a hierarchy of stigma faced by persons with disabilities WDR (2007).

According to Watson & Arson, (2006), increased social isolation, decreased employment opportunities, reduced incomes, as well as, reduced self esteem and self efficiency are consequences of stigmatization. Also, due to fear of stigma rural PWDs try to conceal their disability related problems (Bourke, Sheridan, Russell, 2004). In addition, Children with disabilities have universally suffered biased attitude in form of abuse, poverty, exclusion and Institutionalization, (International Save the Children Alliance, 2001). Another study done by Dhar, (2001) reveals that lack of social support increases the risk of mortality and supportive relationships which is associated with lower illness rates, faster recovery rates and higher levels of health care behaviors.

* **Mental Health and Disability:** With reference to this variable, researches mainly focused in 3 concerning area, which are as follows:

1) Acceptance of Disability and mental Health
2) Mental Health of the challenged in Rural and urban sector
3) Current Scenario in terms of mental health services

* **Acceptance of Disability:** Survivors of disabilities showed, self created adjustments less emotional distress and dependency as well as greater activity with a satisfying life style (Cooper, 1999) mental health services in rural communities has made necessary support for community care and mobilizing rural resources for treatment plans (Wagenfeld, 1990, Ruxyan & Faria, 1992 Santos, 1993). Local mental health professionals are

also providing outreach services & community care teams for mental treatment of rural population (Meyer, 1991).

The importance of mental health as a part of public health and the current limitations in the provision of mental health care have also reflected in print media: mental health was described as a 'depressing scene' (Frontline,10 April 2009). The Tribune, Chandigarh published a series of articles titled, 'Mental disorders go unattended in country' (14September 2009), 'Mental health fights for its space' (20 September2009) and an editorial, 'Restoring mental health' (14 September2009).

Mental Health of the challenged in Rural and urban sector: 21% of the challenged population lives in rural area and 6% among them visits psychiatrists which is very less. Bureau of Census (1988) Bachrach(1983) The ability of rural mental health providers offering services such as suicide prevention, crisis intervention and individual counseling is much limited as compared to urban areas (OTA,1990).

Current Scenario in terms of mental health services: The risk of psychiatric illness in rural & urban areas is same (Bachrach, 1983; Pothier, 1991). Not only mental health services in remote areas are almost nil; poverty, illiteracy and stigma for mental illness act as significant deterrents for the dismal state of affairs. Being female is reported as a risk factor for commonly known mental disorders. Other Indian studies have also shown that poverty and deprivation are independently associated with the risk for common mental disorder in women and add to the sources of stress associated with womanhood (Kuruvilla & Jacob, 2007). It is stated that mental

disorders termed as Common Mental Disorders (CMDs) are most prevalent among those with the lowest material standard of living, especially among those with a long term experience of poverty (Weich & Lewis, 1998). Moreover, the descriptive models of persons with common mental disorders have been described in a number of studies and poverty and socio-economic problems have been cited as one of the most important factors causing emotional distress (Kuruvilla & Jacob,2007).

There is paucity of epidemiological researches on rural mental health.

3. SOCIAL VARIABLES

* **Social Perception and Disability:** Researches exploring the mindsets and perception about the disabled go a long way in serving as a bench mark for further intervention in the area. Social perception based on geographical locations, report coverage of areas from all over India at different locations, viz. Andra Pradesh, Gujarat and also gave views on National Level: Rao (2003), Action Aid (2000).

Researches on social perception focus on three major categories of Religious faith, Based on Karma and Mindset of society.

It is always seen and felt that PWDs are always judged by the society and mostly negatively. In this context, mostly the researcher's analysis is based on perception of our ancestors regarding disability. "Disability is a punishment of God" (Rao 2003), Action aid (2000). PWDs were found to only attend half religious gathering and they also report that they get discouraged for

attending marriage & political participation, (Sevabluman, 2004). There are evident differences in health, education and productivity perception, (Mitra & Sambameorthi, 2008). A number of evidences cited in scriptures focused on the disability as a result of one's actions. The karmic perspective, therefore, attributes disability to our earlier sins and misdeeds (Barquer & Sharma 1999, Coleridge 1993, Miles 1995, Erb, Harris & White 2002). Hindu mythology has portrayed PWDs in negative ways (Bhaenbani, 2003); (Sharma, 2006). Disability occurs due to previous deeds, Gnai (2001), Harna (2001), Ghosh (2005). Bad deeds and sufferings result in stigma & biasness, negative attitude & denial of responsibilities in social life (World Bank Reports, 2007).

Some studies also reflect the mindset and shows that people with mental illness and mental retardation are the people likely to be missed in surveys. (Office of the Registrar **General** & Census Commissioner, **India** (ORGI), 2001). Young people with disability tend to remain excluded from social participation, WDR (2006). Negative perception about the ability to participate in formal education makes them excluded, Gnai (2003) social mindset is negative to respect the inclusion, (IUBR, 2007). Social stigma results in parents to withdraw or discourage them from sending their children to schools (Angela Kohama, 2012).

* **Social Interaction and Disability:** With reference to social interaction of Persons with disabilities, the research review highlights the interaction level of PWDs in the society and focuses on 3-4 aspects. Certain trends, have recognized the challenges faced, inclusion of PWDs in different segments and perception regarding interaction.

On the one hand, where social environment and interaction provides a platform for construing disability identities, on the other hand, the social environment are not conducive and supportive of a disability identity (Brown, 2009; Gething, 1997).

Some educational and social policies promote inclusion to involve and enhance opportunities for adolescent with disabilities (Goffman, 1963; Halm, 1988). Increasing social participation of children and adolescents with disabilities is a major goal of two federal laws, the individuals with Disabilities Education Act, 1997 and Section 504 of the Rehabilitation Act, 1973. Neither law requires inclusion of students with disabilities in regular class-rooms, but both require that a significant effort be made to find an inclusive placement (baker, 1995; Carlberg & Kavale, 1980).

Social connectedness for adolescents with disabilities is of vital importance irrespective of their mainstreaming. Social support, whether from the family or significant others outside the home, can be an important influence on the quality of life of adolescents with disabilities (Emond, Fortin & Picard, 1998; Wallander and Varni, 1998). Integration of PWDs is major and time taking process and received government support in U.K and U.S (Davies, 1995; Social Sciences Inspectrate, 1995b; Vladeck, 1995).

4. DISABILITY RELATED VARIABLES

* **Inclusive Education and Disability:** It is a process of strengthening the capacity of the education system to reach out to the learners who due to some challenge are at a disadvantaged position. However, when they study in a normal healthy setting it has an effect on both the challenged and non challenged group of students **(Policy Guidelines On Inclusive**

In Education, UNESCO, 2009). Inclusion is somewhat beyond and above Integration (integration could be important step forward to inclusion but not in totality, as suitable change or universal design in terms of physical on well as change in curriculum and pedagogy, every step as a measure to include every student/learner). [Save The Children, UK-2008]. With reference to inclusive education various research context have emerged in terms of segregation, integration, policy frame-work/provisions and status of retention duration of learners. In the school dropout rate etc, are reflected as follows:

* **Segregated Education:** Introducing different curriculum in special schools is not inclusion, Angela Kohama, (2012)]. Also focusing on integration by means of strengthening the capacity of all learners is not Inclusion, Angela Kohama,(2012), Singhal (2006), Jha (2002), Hegarty & Alur, SSA report.

Inclusive education has emerged as a cheap alternative to other special education programs, specifically for developing countries, Kalyanpur, Maya(2008), Jangira, NK(1997), UNESCO(1970). The developing countries are also guided by certain policy framework for the Inclusive Education (UN General Assembly 1989, United Nation Decade of Disabled Persons. 13 March 2012, CRC-1989, UN Rules-1993, Salamanca Statement, UNESCO 1994). Later it has been adopted by developing countries like India (Kothari Commission (1966), Joint Review Mission of SSA (2005), SSA Review (2006 & 2007) and by many other countries (Holds worth (2002), Singhal (2006), Pandey (2006).

Inclusive education also talks about accessibility or universal design, Singhal (2006) Angela Kahoma (2012), Hegarty and Alur, importance of early intervention (Aneeta (2000), Taneya(2001) and Sen P-33) with proper development of human resource/manpower (UN General Assembly, 1989, UPEFA/SSA).

* **Accessibility and Disability:** Inaccessibility is a major barrier for full participation of persons with disabilities. The majority of people with disabilities are confined to their homes because they are unable to have access to any of the public places, transportation or services (Mehrotra, 2013).

Employer's family members and PWDs themselves have preconceived ideas regarding their capabilities, accessibility issues and so on. Compared to their able bodied peer's unemployment among PWDs is usually high. The situation of women with disabilities is even worse with more discrimination and fewer opportunities (UNDP, 2011).

Only small percentage of PWDs receives vocational training and the percentage is not increasing that it needs to be. (Singh & Das, Disability and Development in India (2005).

Households with a disabled member are more likely to experience material hardship including, food insecurity, poor housing, lack of access to safe water and sanitation and inadequate access to health care. Brakel (2006), Mitra (2011) Baresford, Rhodes(2008), Eide & Loed (2011).

*** Education and Accessibility:** Basic issue of accessibility for CWDs needs to be changed. School buildings are predominantly not accessible to PWDs, in total only 18% of SSA schools were barrier free and the numbers are even lower in some states like

Bihar and Jammu & Kashmir. A position paper of NCERT on national focus group on education of children with special needs (2005) states that not more than 4 percent of children with disabilities have access to education.

The perception of disability on giving access to children with disabilities has little regard to their participation in the classroom, or the curriculum (Singal, 2006).

PWDs requires improved access to basic education, vocational training relevant to labour market needs and jobs suited to their skills, interests and abilities with adaptations as needed. Many societies are also recognizing the need to dismantle other barriers making the physical environment more accessible and providing information in a variety of formats and challenging attitudes and mistaken assumptions about Persons with Disabilities (UNDP, 2012).

* **Employment and Disability:** Transparency and lack of Information affects the availability and performance. Less than one third of the PWDs population is registered and benefited under Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA) with only 19.48 working days. Sub group on economic empowerment of persons with disabilities' August (2011).

- **Rehabilitation and Disability:** Rehabilitation of CWDs/PWDs has not gained much needed focus from the society and not even covered effectively through any government schemes, policies and acts. Researchers and professionals suggest for mainstreaming the Persons with Disabilities. Government needs to initiate several programs for the empowerment and livelihood opportunities of PWDs.

Pandey & Advani(1995) and gave recommendation in pointers:

- Vocational Training Center
- CBR Rehabilitation
- Legislative Support for Rehabilitation
- Capacity Building
- Technology and rehabilitation
- Manpower development for Rehabilitation

In India, a majority of the Persons with disabilities reside in rural areas where accessibility, availability, and utilization of rehabilitation services and its cost-effectiveness are the major issues to be considered. Roy & Kar (2012).

State governments in India are primarily responsible for implementing laws and distributing social welfare benefits to people with disabilities. States also have considerable scope for deciding priorities among issues related to disability, and in creating legislation suited to the context of their environment's socio-cultural background, Bagchi (2003), Sinha (2004). Some states have been positive in increasing awareness among people with disabilities about commitments and entitlements (Tamil Nadu, Karnataka, and New Delhi) whereas others have lagged in implementing many of the basic entitlements given in the PWD Act of 1995 (Bihar, Maharashtra, Orissa, Uttar Pradesh). World Bank (2007).Although, past work has noted the important but incomplete role played by the state in delivery of services and entitlements (Thomas, 2005).

Obligations to people with disabilities fall under the jurisdiction of state governments and the State List under "Relief of

people with disabilities and unemployable" (World Bank, 2007). In a study of the Indira Kranthi Program which facilitates micro-lending through self-help groups to people with disabilities in rural Andhra Pradesh, it was found that although the program resulted in increased borrowing, education and asset ownership, there was negative to zero effects on the labor market participation of the beneficiaries (Thompkins, 2010). Rehabilitation Centre's (DDRCs) were established with the objective of providing comprehensive services to the persons with disabilities at the grass root level to provide rehabilitation services to PWDs viz awareness generation, early intervention, counseling, therapeutic services like Physiotherapy and Speech Therapy, referral and arrangement for surgical correction through Government and Charitable Institutions. Ministry of Social Justice and Empowerment (MSJE), District Disability Rehabilitation Centers (2010).

For mainstream services, some people with disabilities may require access to specific measures, support services, or training. In this process, involvement of persons with disability is of paramount importance as they give insight into their problems and suggest possible solution (International Classification of Functioning, Disability and Health, 2001).

An integrated approach is required, linking prevention and rehabilitation with empowerment strategies and changes in attitudes, (MNREGA, 2011).

Disability limitation and its screening at an early stage facilitate preventive and rehabilitative measures, so that progression to severe disability can be minimized. This is a vital component in rehabilitation of disabled. It has shown that very few

disabled people get benefit from rehabilitation services in India (Department of Statistics, Government of India, 2003).

The studies on the quality of rehabilitation services are relatively few. Some researches showed that around 50% of the PWDs receive some kind of medical or surgical services, but other types of rehabilitation services were poor. Besides, it was reported that only 2%-3% of the disabled have access to such services (Thomas and Pruthvish , 2004).

Unfortunately, the mindset that disability in the community is a minor problem and does not need much of intervention still prevails. However, in reality, it is a social problem where the disabled population becomes a liability to the society. Alma Ata declaration in 1978 stated that a comprehensive primary healthcare should include primitive, preventive, curative and rehabilitative care (Sharma and Praveen, 2002).

A study from 22 countries viz. Asia, Africa and Central America coupled with 29 reports on the outcomes of rehabilitation-in-the-community programmes in low and middle income countries published between 1987 and 2007. Interventions included home visits by trained community workers who taught disabled persons skills to carry out activities of daily living, encouraged disabled children to go to school, helped find employment or an income generating activity, often involving vocational training and/or micro-credit Velema, (2008). This supports the scanty number of researches in the area over a decade.

Further, Socio-Economic Rehabilitation (SER) shows that both approaches aim to become part of a community development process. The basic assumption is that people with disabilities will

benefit most from being included in mainstream programmes implemented in their own community. Finkenflügel and Rule (2008). Besides providing a wide range of possible services to disabled persons, rehabilitation seeks to change the attitudes that prevail in society as a whole and promote the integration of disabled people into society with equal rights and opportunities (Corneille, 2000).

CHAPTER-2

METHOD

METHOD

TOWARDS THE PROBLEM

Historically, people with disabilities subjected to prejudice and discrimination, have suffered exclusion and a significantly reduced quality of life. Societies where "normalcy" and "functionality", have been defined rather narrowly, persons with disabilities have little access to social, political and economic structures. Such a state of art with felt exclusion and discrimination makes the challenged more vulnerable and alienated from the mainstream.

The issue of disability has been addressed in the contemporary scenario by champions of human rights and social justice, though it appears to be more at a level of advocacy, particularly, when such efforts are piecemeal in the light of inadequate empirical researches and their documentation. More validation in the form of empirical researches is the need of the hour. The present research is an attempt in this direction.

Improvement in the Quality of Life of the persons with disabilities (PWDs) can be brought about by (a) Rehabilitation and Empowerment of the PWDs by action researches focused on **creating change in their belief systems, behavior and coping with their life and the world** and (b) **bringing about a change in their existing physical and social environment**, which would give them more opportunities for greater participation and

inclusion. Both the aforementioned strategies are interlinked and a change in one would ensure a change in the other.

In the face of paucity of researches on the rehabilitation of the PWDs, whatever efforts **have been made by the government in terms of provision of infrastructure facilities or other services under any scheme, tend to lose their efficacy over time with no follow ups. Further, the sustainability of the project, as well as, the effect of the same on the life of PWDs is almost left unexplored.**

The mental health status and problems of the marginalized groups have been of late attracting the attention of the researchers; however, the group of PWDs somehow has been left unattended with reference to their mental health status and issues. Although, ironically, the stress and anxiety along with the inability to reach the same platform of psycho-social competence as their counterparts tends to, make the PWDs more vulnerable to stress related problems and other mental health issues.

The voices of the disabled citizens seldom reach the policy makers. Disability and development of the PWDs is somehow still experiencing huge gaps between inception of a policy and its implementation. The actual beneficiaries still wait in silence for their turn to come. What more, they are largely seen as recipients of charity and not as contributors to the nation's development. There is a felt need to understand the issue of inclusion of PWDs, especially in the rural belt at the grass root level. Despite the policies and the improvising in various acts, viz. National Trust Act 1999, PWD Act, 1995, UN

Convention on the Rights of Persons with Disability, 2008, **the realistic plane still shows strong shades of discrimination and exclusion of the PWDs by people at large robbing them of their basic dignity and personhood, on the one hand and social support on the other.**

The researcher is familiar with such psychological trauma of exclusion at an experiential platform**, being a patient of Cerebral Palsy since birth.** Adler in his theory of Organ inferiority describes how people who found themselves born with certain defects develop feelings of inferiority and start taking action for their weaknesses. Adler believed that inferiority complex, (where an adult feels inferior to others), is only developed if the child has experiences that his organ inferiority makes him less worthy than others. However, he also said that if the person manages to compensate properly for his inferiority feelings then he will pass through this phase successfully and become a mentally healthy person. On the other hand if the person fails to compensate for his weaknesses, he might develop an inferiority complex and believe that he is less worthy than others (Adler, 1956). Instead of yielding and succumbing to the medically induced pain of cerebral palsy and the psychosocial discrimination, the researcher not only fought it out bravely but also conquered the challenges that came his way.

Experiencing and empathizing with Persons with various challenges and Disabilities, the researcher felt an intense urge to do something substantial for enhancing the quality of life of such challenged people. With such a strong conviction and a driving force to capacitate and empower PWDs at rural belt, the researcher started a civil society organization in the name of School for

Potential Advancement and Restoration of Confidence(SPARC)India in the year 1996 with the mission 'To serve and create a barrier free environment for marginalized sections particularly the disabled where they can realize their rights and lead a life of dignity.' The organization started its urban community based rehabilitation program for PWDs in the year 1996 which was soon followed by the rural community based rehabilitation program in Nindura block of Barabanki district in the year 2009.

This study gave the researcher an opportunity to explore the social, psychological, physiological and emotional needs/conditions of disabled people.

The issues pertaining to disability which intrigued the researcher are being addressed below briefly:

- The social stigma that is associated with disabilities and disabled people needs to be dealt with at a macro level, creating a positive and healthy environment and attitude towards both the disabled and the disability. Though at theoretical and policy level, the concepts of mainstreaming of the challenged people has created in roads, however, a lot of effort needs to be put in to bring in the same concepts to the belief systems of a lay person in a country like India.
- Empirical follow ups are also needed to test the validity and efficacy of the efforts that have been made to bring positive change in the PWDs in terms of their inclusion.
- **Researches are needed to explore the mental health status** and well-being of the PWDs. Most of the **researches focus largely on the socio-demographic conditions of the**

PWDs but there is a huge gap in the researches taking care of the self concept, self esteem, support system and other emotional stress in the life of the PWDs.

- The need of the hour is researches which would imbibe an **inclusive paradigm** of social support in them i.e., the PWDs and their support system in terms of their care givers need to be taken together in the researches. On one hand, it would increase the joint understanding of both the PWDs and their care givers. On the other hand, it would create an environment of empathy for the disabled people and also provide inputs for action program for psycho-social support of the PWDs.

- It is also essential to focus on the deep embedded cultural stereotypes especially with reference to gender i.e. **sex stereotypes,** both in terms of the PWDs as well as the care giving. The bringing up of the male and female children with disability in the Indian context tends to be different. Furthermore, it also limits their growth and coping with their challenges.

  Moreover, it has been noticed that the researches on **care giving** largely are limited to the sample of care givers to chronically ill people viz. AIDS, Cancer, geriatrics etc. But unfortunately there is a huge paucity of researches on care giving of the PWDs.

Despite radical changes in the social fabric, the rural India still holds on to the philosophy of 'Vasudhaiv Kutumbakam' which tends to reinforce the image of community as a family, however, if

the same community does not accept a person with disability, it leads to social rejection detrimental and hazardous for the growth and development of persons with disability.

Towards the end of 1995 a group of like minded individuals in Lucknow felt the need to start social services for PWDs because such services for them were almost non-existent in the state. A series of meetings led to the formation of an NGO for the PWDs by the name of SPARC-India. The acronym of SPARC-India was spelt out as School for Potential Advancement and Restoration of Confidence (SPARC-India). Established in the year 1996, it is committed to work for Persons with Disabilities (PWDs) through its Community based Rehabilitation (CBR) Programs in the urban slum areas of Lucknow and Nindura and Deva block of Barabanki District. These programs were centrally focused upon bringing about **inclusion** of BPL PWDs with a marginalized status in the mainstream. An intervention program provides services and facilities to the PWDs, Children with Disabilities (CWDs) in more than 200 villages of Barabanki district and slum areas of Lucknow district.

The efforts of SPARC India got a reinforcing boost in a UK Based Action Aid project entitled **"Rural Community Based Rehabilitation Program for PWDs in Deva Block, District, Barabanki."** Initially the project took its sample of PWDs from 50 villages. However, the encouraging results motivated the sponsors to extend the coverage area to 140 villages. It is a multi thronged approach. The factors which facilitated their inclusion in mainstream included Medical Rehabilitation, Vocational Training,

Education, besides providing them social security and personality development inputs. The same is mentioned below briefly:

Medical Rehabilitation: *SPARC-India* provides support through medical aid and appliances facility to Children/Persons with disability. The organization also assists in the Certification of the children and persons with disability.

Vocational training: For the mainstreaming through sustained livelihood sources organization provides vocational trainings to PWDs so that eventually they may attain an independent status (economically) in life.

Education: For the inclusive education, organization provides support for the Liasoning and sensitization trainings to district/Block authorities related to the Education sector.

Social security: Organization supports PWDs to make their Disability certificates and aware about their rights and entitlements. Also, enabling them to access bus pass, rail pass, scholarships, pension and financial assistance etc.

Personality development: The beneficiaries/PWDs were given various communications, leadership and skill building trainings by the organization to build their capacity in taking initiatives and ownership of the program run by SPARC-India and this was done with the purpose of making them independent and help them in achieving their dreams in the due course of time.

Table 2.1 mentioned below gives a summary of the sample of the inclusion project:

Table - 2.1: Distribution of the sample for Inclusion project according to gender, age and type of disability

Type of Disability	***Gender***			***Age***		
Disability	***Male***	***Female***	***Total***	***Less than(<) 14***	***More than(>) 14***	***Total***
Locomotor Impairment	157	75	232	109	123	232
Speech, Hearing Impairment	69	37	106	50	56	106
Visual Impairment	60	61	121	18	103	121
Mental Retardation	43	19	62	115	47	62
Epilepsy	12	5	17	3	14	17
Leprosy	18	9	27	4	23	27
Multiple Impairment	278	233	511	70	441	511
Total	637	439	1076	283	821	1076

Since, the researcher was also the principal investigator of the project and could relate to the change in the lives of the PWDs, as a result of this intervention for inclusion, there was a desire to empirically validate the efficacy of the intervention and that's how the present research came into being. The distribution of the sample for the Inclusion project as per gender, age and type of disability as illustrated in Table 2.1, clearly shows six types of disabilities, besides the category of multiple impairments. The final

sample which served as the beneficiaries of the project was 1076 individuals.

Objectives

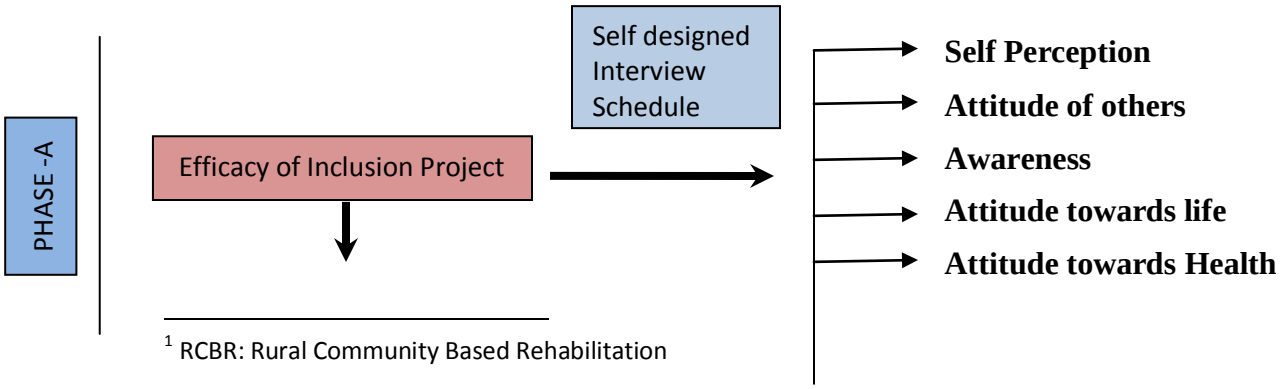
1. To explore the efficacy of the RCBR[1] project on the PWDs perception of self and the world in **Deva Block, District, Barabanki."**
2. To explore the health perceptions and mental health status of the challenged people and their caregivers from Deva Block of Barabanki District.
3. To explore the Self Other Relatedness of the challenged people from Deva Block of Barabanki Districts.

Design

The study has been conducted in two phases:-

Phase-A: serves as a follow up of an inclusion intervention program on Rural Community based rehabilitation (RCBR).

Phase-B: is an exploratory research design with an ex post facto orientation to explore the health perceptions and mental health status, as well as, self other relatedness of the PWDs.



[1] RCBR: Rural Community Based Rehabilitation

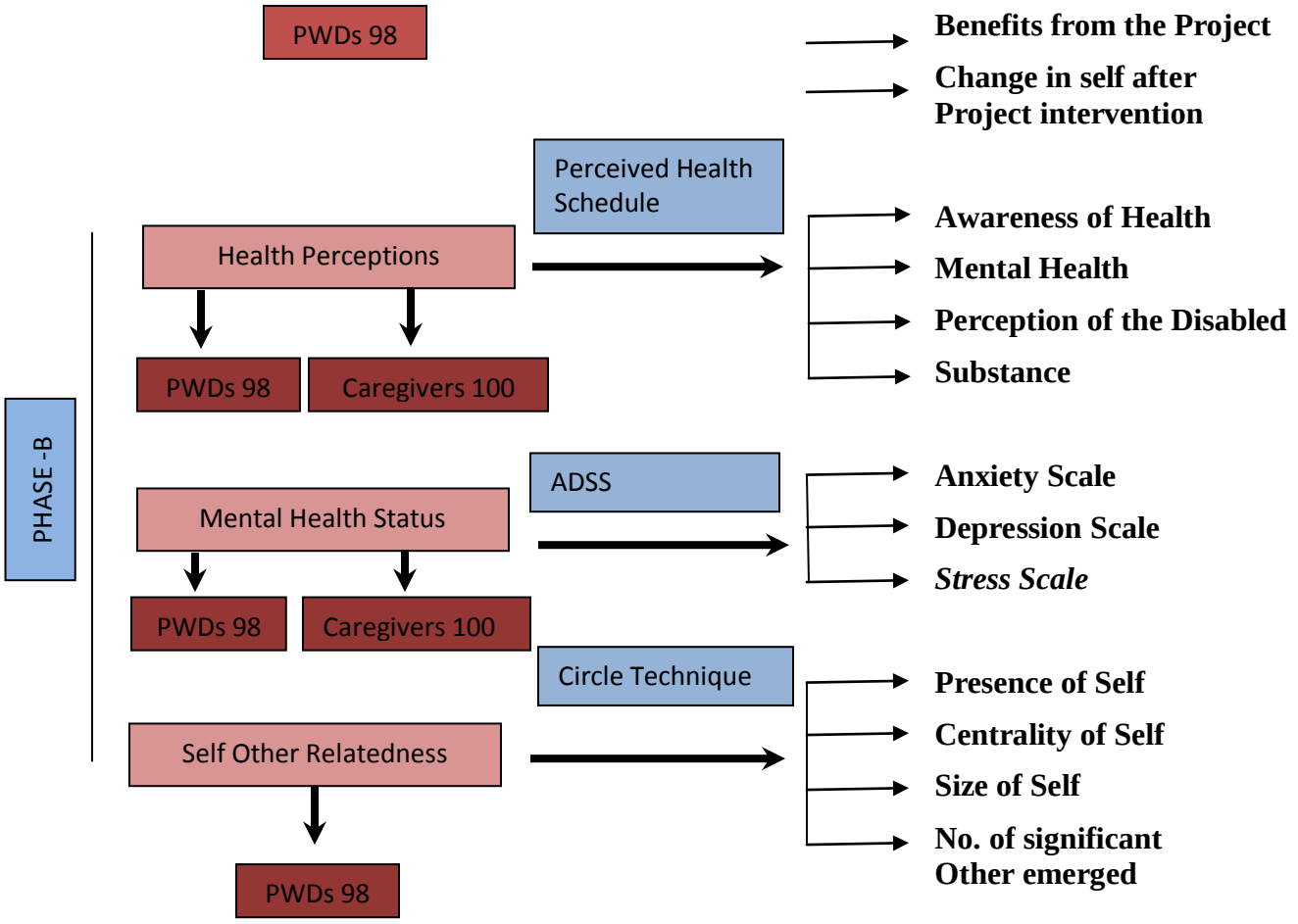
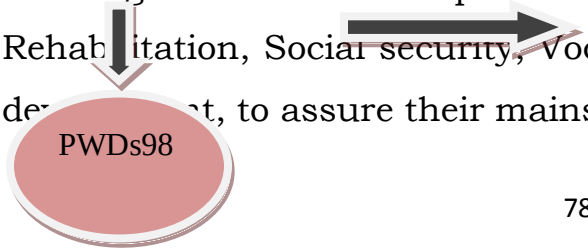


Figure 2.1. : LEVELS OF CONCEPTUALIZATION (Phase A & Phase B)

VARIABLES FOR PHASE - A

I. INDEPENDENT VARIABLE

Intervention Programme on Rehabilitation of the Challenged: SPARC India initiated Community based rehabilitation program for Children/Persons with Disabilities in Deva block which primarily focused on issues pertaining to health, education, livelihood and social security. The inclusion program, had been focusing on various aspects of a PWDs life, viz. Medical Rehabilitation, Social security, Vocational Training and Personality development, to assure their mainstreaming in the society.



II. DEPENDENT VARIABLE

Perceived efficacy in terms of Perception of self and the world view: As mentioned in **Section 1,**

Rationale: After the intensive intervention work done in the field area of Deva block, it was felt essential to empirically measure the improvements in the lives of the PWDs in the program. Through this self-designed interview schedule loaded on 7 dimensions, viz. self perception, attitude of others, awareness, attitude towards life, attitude towards health, benefits from the project and change in self after project intervention.

VARIABLES FOR PHASE - B

I. INDEPENDENT VARIABLE

Challenged Status: Challenged status is the consequence of an impairment that may be physical, cognitive, mental, sensory or developmental or some combination of these. A person might be challenged by birth or any time during the life time. ***The operational definition of the challenged status in the present research is the people with cerebral palsy (challenged) and their guardians (non-challenged).***

II. DEPENDENT VARIABLE

(a) Health Perceptions & Mental Health Status: Health perceptions are determined not only by one's awareness and beliefs about health but also upon one's health status. 'Mental Health is the capacity of individual, group and environment to interact with one another in ways that

promote subjective wellbeing ,optimal development and use of mental abilities, achievement of individual and collective goals consistent with justice and attainment and preservation of conditions of fundamental equality'. WHO (2001). Operationally, mental health has been defined in the present study in terms of the responses obtained on the self devised ***Perceived health Schedule*** and ***Anxiety Depression and Stress Scale (ADSS)*** (Bhatnagar, Singh, Pandey, Sandhya, & Amitabh 2011). Operationally, the health perceptions are the responses of the challenged and their care givers on a self developed schedule.

Rationale: The grassroot reality of health scenario in rural sector particularly the challenged show an extreme inadequacy both in terms of health services and researches. No developmental programme can be successfully chalked or implemented if the state of art in terms of perceptions and status is not explored. Mental Health unfortunately has been an issue of rather low priority in our country and needs to be taken up seriously. There is a general agreement that mental health is more than an absence of mental illness. As the review suggests section, the researches focus more on the socio-demographic aspect of disability. There appears to be huge gaps in the assessment of mental health and Perception of disability.

(b) Self Other Relatedness: Conceptually relationships may be understood as "Relationships often described are more or less close and a participant's perception of the closeness of a relationship may affect its delayed course. Closeness implies

independence between the participants" (Hinde-1997). In the present study, the self other relatedness is operationally defined as responses on **Circle Technique (Thrower, Bruce and Walton, 1982)**.

Rationale: Relationship is also perceived as an index of mental health and is considered as an important parameter to measure mental health. Even in today's society the stigma of disability has an adverse affect on the relationships of a person with disability and his micro relational world. Hence, self other relatedness is also a vital variable of the present research.

Sample: The sample has been taken from villages of Deva block of Barabanki district of state of Uttar Pradesh. The relevance of picking up the sample from rural sector stems from the need to explore mental health of such people which constitutes approximately 70% population of India.

Sample Distribution across various phases

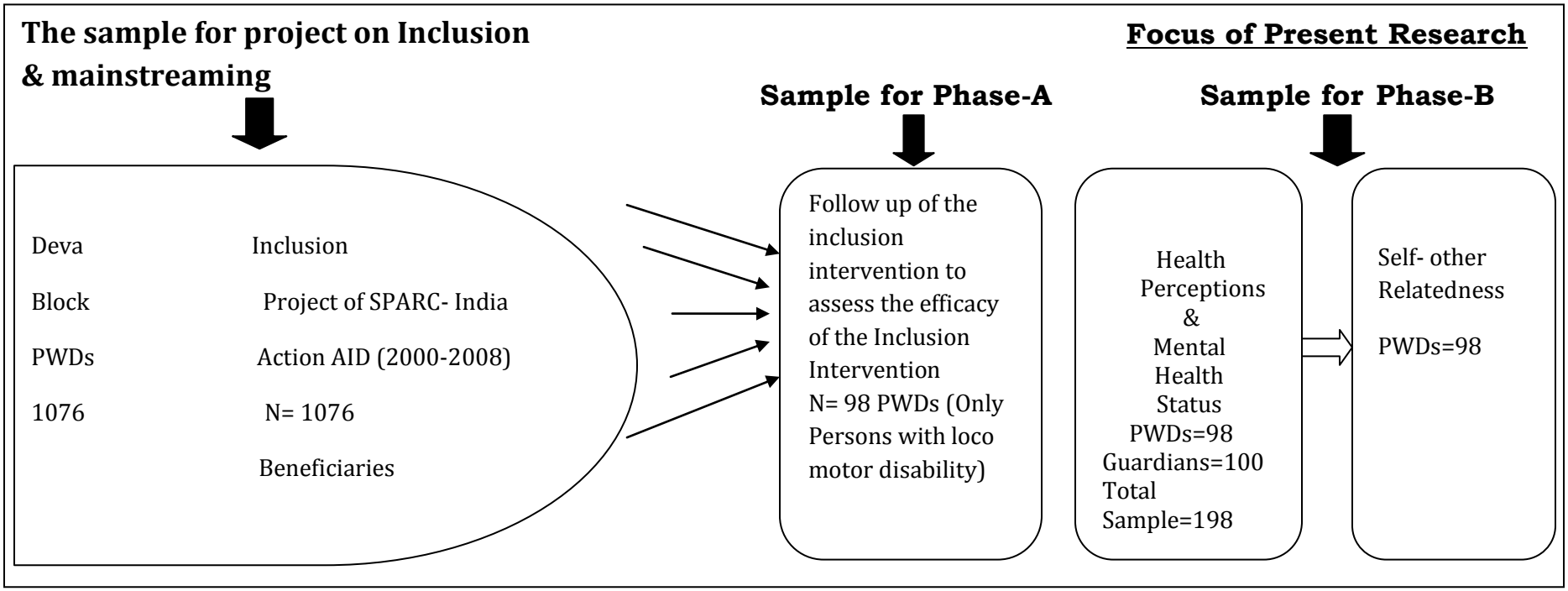


Fig. 2.2 : Sample Distribution across various phases

PROFILE OF DEVA BLOCK OF BARABANKI DISTRICT

Barabanki District is an administrative district of Uttar Pradesh located in **Awadh** region. Barabanki District is situated about 29kms in the east direction of **Lucknow**. Deva is a development block of district. As of 2001 India census,[2] Deva had a population of 12,819. Males constitute 53% of the population and females 47%. Deva has an average literacy rate of 45%, lower than the national average of 59.5%: male literacy is 51% and, female literacy is 38%. In Deva, 17% of the population is under 6 years of age.

Deva Sharieff traces 150 years of history, where a famous Mosque was built by Thakur Panjam Singh. A temple is also located in the same campus. The Hindus and Muslims in the area live together with secular and communal harmony. The village in the area as old as 250 to 300 years Because of the mosque, the place is internationally known for its pilgrimage.

The percentage of disability in the research area accounts to 4.4%, which includes cataract and chronic illness. This ratio is high compared to the national percentage of 2.68%.The research area also suffers from some key problems like literacy, health and hygiene, sanitation and transport.

Rationale for selection of Deva block, Barabanki:

The purpose of the study is to identify the challenges and mental health status of PWDs in rural area. Through SPARC-India's (voluntary organization) base line survey District Deva was identified as having large number of PWDs facing critical challenges related to accessibility and infrastructural barriers.

It was found in a base line survey that Deva block have large population of persons with disability and it was very important to understand the problem and status of most marginalized and vulnerable section of the society to mainstream them.

Sample Characteristics

A large number of the PWDs after the inclusion project migrated to other places for livelihood and other purposes. This speaks for the gap in the sample contacted to measure the efficacy of the intervention program in the present research. Further, the present research only addresses Loco-motor impairments particularly Cerebral Palsy. Hence, 98 PWDs from the Inclusion project serve as sample of the present research.

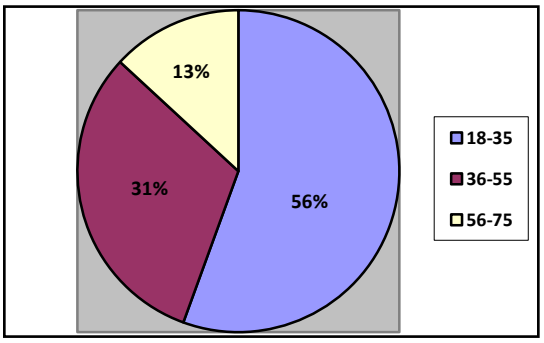


Fig. 2.3 : Distribution of sample according to Age

- **Age:** The age of the sample taken for the present study ranges from 18-75 years. However, the study majorly comprises of the sample between 18-35 years, which accounts to around 56% of the total sample and there is only 13% of the sample that falls under the age group of 56-75. Further 31% of the sample falls in the age group of 36-55 years.

- **Gender:** The present study has tried to ensure the participation of females also in the research tools. The study comprises of 65% of males and 35% of the females in the total research sample.

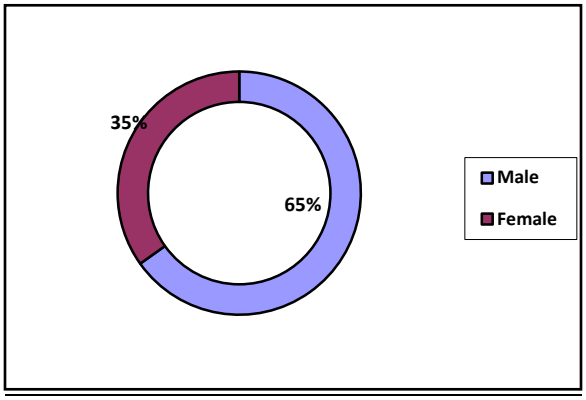


Fig. 2.4: Distribution of sample according to gender

Assumptions

In the absence of any empirical base, specific hypothesis could not be framed. However, certain hunches have been drawn by the researcher:-

1. It was assumed that there would be a positive change in the perception of self and the world view of the PWDs after the Intervention project.
2. The PWDs would have lower awareness regarding health perceptions as compared to their guardians.
3. PWDs would have a reduced rate of Anxiety, Depression and Stress as compared to the guardians.
4. The self other relatedness would show more of a fused/enmeshed relationship in compassion to other types of relationships.

Tools and their Administration:

1. **Efficacy of Intervention:** In order to gather information pertaining to the post intervention status of the PWDs, an interview schedule

was developed to measure the efficacy of the program at two points of time.

a. **Development of the Post-Intervention Follow up Interview Schedule-** The schedule was self-designed. The schedule had 7 dimensions all of which revolved around the pre and post intervention effect of the inclusion project. The seven dimensions are as follows: Self Perception, Attitude of Others, Awareness, Attitude towards life, and Attitude towards health, Benefits from the project and Change in self after project intervention.

b. **Administration of Perceived Health Schedule-** The perceived Health Schedule was individually administered on all subjects. After establishing rapport with the subject, following instructions were given,"स्पार्क इण्डिया द्वारा संचालित की गयी परियोजना के प्रभाव हेतु हम आपसे कुछ सवाल के उत्तर देना चाहते है कृप्या निःसकोच होकर उत्तर दे। यकीन रखिए आपके जवाब हम तक ही रहेंगे। हम आपसे कुछ प्रश्न पूछेंगें,उनके जवाब आप पूरी ईमानदारी से दें।" After ensuring that the subject had understood the instructions questions were asked and responses noted verbatim by the researcher. It was taken care of that the language used was Hindi.

c. **Analysis –** The data obtained from Interview Schedule was exhaustive and it was subsumed into mutually exclusive categories after content analysis. Thereafter, percentage analysis was done.

2. **Health Perception Interview Schedule:** In order to gather information pertaining to health perception and Mental Health, an interview schedule was developed.

   a. **Development of Perceived Health Schedule-** Initially the schedule had 30 items. A pilot study was done on 10 Persons with Disabilities to see the comprehensibility of these 30 items of interview schedule. These 30 items were loaded on 2 dimensions- (i) Perception of Physical health consisting of awareness of 'health' related concepts, health status and coping. (ii) Perception of Mental Health which pertains to awareness of Mental Health coping, status, prerequisites etc. Most of the sample was illiterate so the perceived health schedule was made in Hindi. Almost all the items were kept open ended to obtain information in detail.

   b. **Administration of Perceived Health Schedule-** The Perceived Health Schedule was individually administered on all subjects. After establishing rapport with the subject, following instructions were given,"हम आपकी रोज़मर्रा की जिंदगी से जुडी कुछ बातें जानना चाहते हैं। यकीन रखिए आपके जवाब हम तक ही रहेंगे। हम आपसे कुछ प्रश्न पूछेंगें,उनके जवाब आप पूरी ईमानदारी से दें।"After ensuring that the subject had understood the instructions questions were asked and responses noted verbatim by the researcher. **Analysis –** The data obtained from Interview Schedule was exhaustive and it was subsumed into mutually exclusive categories after content analysis. Thereafter, percentage analysis and significance of the difference between percentages were calculated.

3. Anxiety Depression Stress Scale (Bhatnagar, 2011):

In today's society it is very likely that the majority of people will experience symptoms associated with stress, anxiety and depression at some point. For many of us, pace of modern life and the rapid technological changes, cause us constantly to feel unable to cope with the demands that are put upon us. These demands come for many different sources– home, relationships, money, job, health, self-esteem etc. leading to anxiety, depression or stress.

Anxiety and Depression often occur together and there exists a close relationship between their symptoms. Although mental disorders include a range of illnesses (such as anxiety, schizophrenia, and autism), depression is the most common and is pervasive worldwide (Worley, 2006).

Forty-three per cent of all adults suffer adverse health effects from stress. 75 to 90 per cent of all patients visit to the physician are for stress-related ailments and complaints. Stress is linked to the six leading causes of death – heart disease, cancer, lung ailments, accidents, cirrhosis of the liver and suicide, (Symptoms of stress, 2010). In recent years, population based research has demonstrated higher risk for depression and suicide in those who are unemployed (Bartley, 1994; Lewis & Sloggett 1998), those who have relatively lower income (Weich & Lewis, 1998), and those who have relatively lower standard of living (Lewis, Bebbington, Brugha, 1998).

Therefore, there is a need for an appropriate assessment technique inclusive of all three states of anxiety, depression and stress besides being bilingual and which is comprehensible for the illiterate and marginalized groups.

(a) Development of the ADSS:

The researcher feels that there is a strong need for creating a more sound epidemiological base of Mental Health problems especially for the rural masses and people living in difficult circumstances viz. slum dwellers, marginalized groups, PWDs etc. Hence, there is a need for an assessment tool which would explore their anxiety, depression and stress in their context, is bilingual and easy to understand.

Moreover, the researcher also felt a need to assess the three dimensions (anxiety, depression and stress) on the same tool; hence, issues sensitive to Indian setting were taken up.

In the development of the items physical, cognitive emotional and behavioral manifestations of anxiety, depression and stress were considered carefully and included in the items. The items included in the tool also corresponded to the diagnostic criteria of DSM-IV-TR and ICD-10. The empirical base of the items was ***Depression Anxiety Stress Scale by Lovibond (1995), Body Sensation Questionnaire by Chambless, Caputo, Bright and Gallagher (1984), Self Rating Anxiety Scale by Zung (1971), Standford Acute Stress Reaction Questionnaire by Cardena, Koopman, Waelde and Spiegel (2000), Hamilton (1959), Sinha Anxiety Scale (Sinha,1966), PTSD Checklist-Civilian (PCL-C), Anxiety Scale by Srivastava and Tiwari (1988), Self Reporting Questionnaire (Harding, De Arango, Baltezar et al., 1980) and General Health Questionnaire (Goldberg and Williams, 1988).***

A scale of 63 items was developed (25 items of anxiety, 19 items for depression and stress each) in English. After that back translation method was used to translate the items in Hindi with the help of four professionals and they were requested to again translate it into English.

Those items which maintained the same meaning after the back translation were retained. Thus, of the 63 items, 48 items which carried similar meaning and context with the original items were retained. Clarity and comprehensibility of the expression was one of the major criterions of development of the items.

Out of 48 items was undertaken on a sample of 20 people to explore the comprehensibility and endorsement of items and all the 48 items were retained.

To assess the reliability of the scale the items were administered on a sample of 1177 participants (972 non-psychiatric and 205 psychiatric individuals). The obtained reliability for anxiety, depression and stress subscales as measured by Cronbach's Alpha is 0.76, 0.75 and 0.61 respectively and when measured by Spearman-Brown coefficient it is 0.86, 0.86 and 0.76 respectively.

The scale compromises of 48 items divided into 3 subscales which are:

Anxiety Subscale – It compromises of 19 items (Item number:1,2,7,11,14,15,18,20,21,24,25, 28,32,34,35, 39, 41,45, 47) covering various symptoms that are manifestations of anxiety.

(i) Depression Subscale – It compromises of 15 items (Item number: 6,9,10, 13, 22, 26, 27, 31, 33, 37, 38, 42, 44, 48) representing the different symptoms of depression.

(ii) Stress Subscale – It is a scale having 14 items (4, 5,8,12, 16, 17, 19, 23, 29, 30, 36, 40, 43, and 46) and they are covering the symptoms that people experience in the state of stress.

(b) Administration of Anxiety Depression Stress Scale:

The Anxiety Depression Stress Scale was individually administered on both the PWDs and their guardians. After establishing rapport with the subject, following instructions were given: "हम सब अपनी जिंदगी में चिंता, तनाव व दुःख अक्सर महसूस करते है। हम आपसे आपके रोजमर्रा की जिंदगी में महसूस किए जाने वाले चिंता,

तनाव व दुःख से सम्बन्धित कुछ प्रश्न पूछेगे। यदि आपको लगता है कि आप अक्सर ऐसा महसूस करते है तो अपना जवाब हाँ में दीजिए। आपके जवाब गोपनीय रखें जाऐंगे। अतः ईमानदारी से उत्तर दें।" After ensuring that the subject had understood the instructions, questions were asked and the responses of the items were noted in terms of 'Yes' or 'No'.

(c) Scoring and Interpretation:

Each item is scored 1 when endorsed "Yes" and 0 if endorsed "No". The range of the score is 0-19 for anxiety subscale, 0-15 for depression subscale and 0-14 for stress subscale. Higher score indicates experiencing greater anxiety, depression and stress and vice-versa.

Interpretation of the obtained scores is done on the basis of mean and SD, cut off points that are in terms of percentile scores and quartile deviations.

4. Circle Technique

a. Development of the Tool – Thrower, Bruce and Walton (1982) developed a technique to explore the relationship dynamics and systems with the help of circle drawing. In the perceived life space these circle drawings illustrate, in graphic form, the patterns of closeness, distance and power in a family and alliances and boundaries. The tool serves as a rich source of information concerning family dynamics, self other relatedness and networking.

b. During the pilot study the researcher again observed that majority of the sample faced difficulty with pen/pencil. Thus, this tool was

again modified and they were provided with different sizes of Bindis to form the circles.

c. Administration of circle technique – The subject was asked to denote her own 'self' and 'significant persons' of her life in the life space (shown as a big circle). The instructions given for this technique were as follows:

"यह गोला आपके जीवन क्षेत्र/जिंदगी का दायरा है। हम आपको छोटी बड़ी सभी प्रकार की बिंदीनुमा गोले दे रहे है। इन बिंदियों की सहायता से आप खुद को तथा अपनी जिंदगी के महत्वपूर्ण लोगों को (जो आपकी जिंदगी में बहुत मायने रखते है) उनको दिखाऐं। ये बिंदीनुमा गोले छोटे भी हो सकते है (0) और बड़े भी हो सकते है (6)। यह इस बात पर निर्भर करेगा कि अमुक व्यक्ति आपके जीवन में कितना महत्वपूर्ण है व कितना मायने रखता है। यदि किसी व्यक्ति की मुत्यु हो चुकी है लेकिन वह आज भी आपकी जिंदगी में बहुत महत्वपूर्ण है, तो उसको भी आप इस गोले में दिखा सकते है। प्रत्येक गोला किस व्यक्ति को दिखा रहा है उसका नाम अथवा रिश्ता अवश्य बताऐ। आपके द्वारा दी गई यह जानकारी हमारे पास ही रहेगी तथा गोपनीय रखी जाएगी।"

After assuring that the subject has understood what she/he has to do, they were provided with bindis to form the circles. As most of the subjects were illiterate the researcher took the precaution to write in each circle after asking the subject the identity of the significant other for each circle.

d. Analysis and Scoring – Responses in terms of various dimensions of life space like presence of self, number and variety of significant others, centrality of self in the life space, size of self in comparison to others and type of relationship pattern i.e. single dominant, double dominant, enmeshed or emotionally divorced type were scored.

CHAPTER-3

RESULTS AND INTERPRETATION

RESULTS AND INTERPRETATION

In line with the purpose of the present research, the current research was conducted in two phases, wherein the first phase focused upon exploring the efficacy of interventions given to the PWDs in the UK aided inclusion project. The second phase pertained to exploring health perceptions and mental health status of PWDs and guardians and self other relatedness in the PWDs. Hence, the results are also being discussed in two sections. Section 1, pertains to the follow up, whereas Section 2, addresses the health perceptions and self other relatedness of the challenged and their caregivers.

PHASE A– ***Efficacy of the Inclusion Intervention "Rural Community Based Rehabilitation Program for PWDs in Deva block, District Barabanki".***

The efficacy of the inclusion project in terms of the follow up was assessed for two periods of time i.e. pre and post intervention as mentioned in **Section 2,** Chapter 2. This assessment explored the extent of change in the perception of self and world view. This was measured with the help of a self developed schedule loaded on seven dimensions as listed below:

1. Perception of self
2. Perception of self in relation to others
3. Behaviour of others towards PWDs
4. Attitude of PWDs towards life
5. Perception about health and health related problems
6. Benefits from the program
7. Changes in self after the intervention program.

The results pertaining to each dimension is given below:

1. PERCEPTION ABOUT SELF: THEN AND NOW

In order to obtain the information regarding the selfhood the question asked was: "परियोजना में शामिल होने के पहले आप खुद के बारे में कैसा महसूस करते थे और अब क्या सोचते हैं ?"

Pre-dominantly there were 3 kinds of response categories that emerged, viz.:

- Self Perception
- Perception of self by others
- Mood states & feelings

Table 3.1 : Illustrate the typical responses, as well as their Distribution for the two periods of time

Categories	Typical examples of responses	
	Pre-Intervention	Post-Intervention

Self Perception	• संस्था में शामिल होने से पहले मेरे अन्दर नकारात्मक सोच थी कि मैं कुछ भी नहीं कर सकता हूँ न पढ़ लिख सकता हूं। न रोजगार कर पाऊंगा, न इधर उधर आ जा पाऊंगा। • जब मैं परियोजना में शामिल नहीं था, तब मेरे अन्दर नकारात्मक सोच भरी थी, कि मैं अपना काम स्वयं नहीं कर सकता हूं माता–पिता कब तक मेरी मदद करेगें इस बात से मुझे ज्यादा निराशा थी।	• मैं बस यही सोचता हूँ कि स्पार्क इण्डिया मेरे लिए कोई न कोई नया रास्ता जरूर दिखाएगी। मै कुछ कर सकता हूँ। • मैं अब यही सोचता हूं कि अगर मुझे आर्थिक सहायता मिल जाए तो मैं कुछ काम करूं।
Perception of self in relation to others	• मैं अपने आप को एक समाज से अलग महसूस करती थी। अपने प्रति मन से एक हीनभावना सी प्रतीत होती थी कि मैं सबके साथ मिलजुल कर कार्य नहीं कर पाऊंगी।	• संस्था से जुड़ने के बाद जानकारी मिली कि मैं भी समाज का एक हिस्सा हूं और सभी लोगों के साथ मिल जुल कर कार्य कर सकती हूँ।
Mood states & Feelings	• संस्था में शामिल होने से पहले मैं अपने को एकदम मायूस एवं निराशा जनक महसूस करता था। • हमको महसूस होता था कि इस जिन्दगी में कुछ नहीं है। मन टूटा–टूटा सा लगता था कोई किसी प्रकार की योजनाओं के विषय में जानकारी देने वाला नहीं था।	• संस्था में जुड़ने से मुझे एहसास हुआ कि कोई मददगार हम लोगों का भी है। **अब लगता है जीने का कुछ मतलब है ।** • संस्था के जुड़ने से मुझे बहुत अच्छा लगा

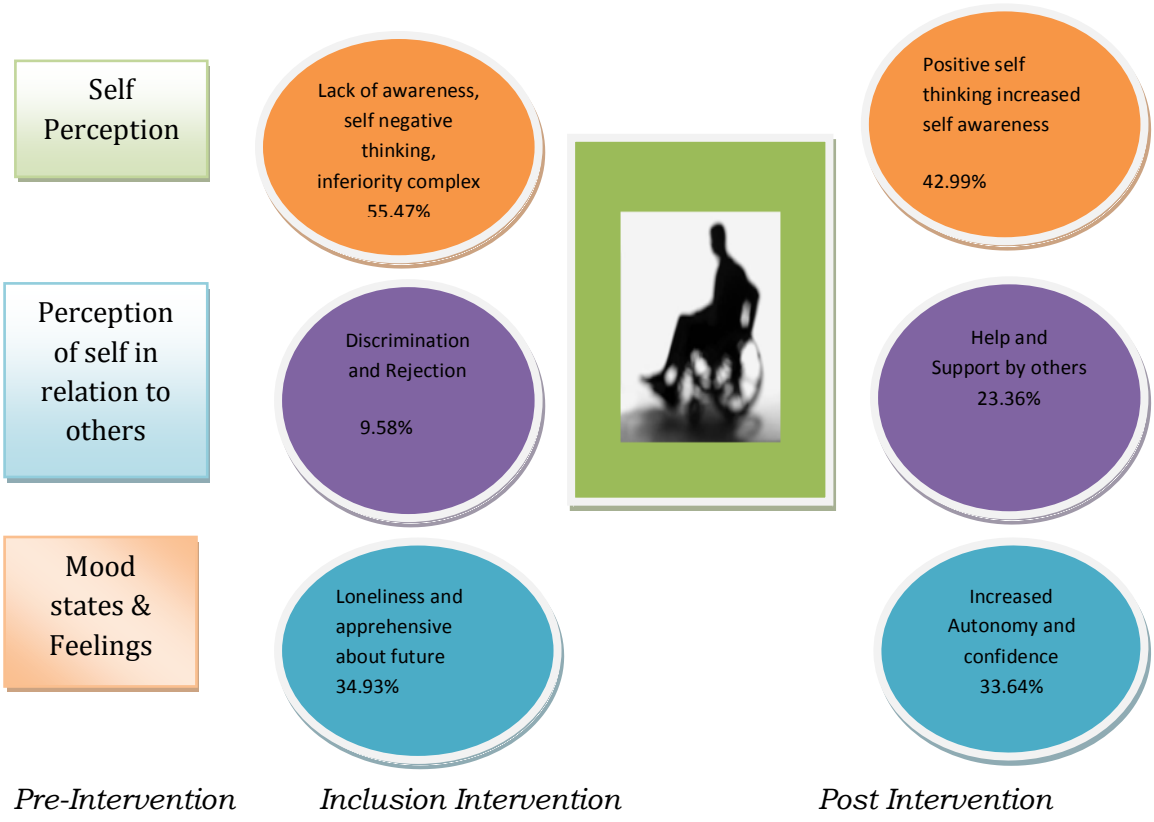


Fig. 3.1 : Perception of self for the pre & post intervention on inclusion

The selfhood shows a definite change in the perception of PWDs, wherein the self perception prior to the inclusion intervention generated responses largely loaded on negativity, inadequacy and inferiority. The responses of 55.47% PWDs reflected their negative Perception about own self. However, after the intervention done, 42.99% of responses clearly show that the intervention program added value to their lives in terms of positive thinking and increasing their awareness level over their rights and entitlements. After intervention, it was noticed that the negative thinking amongst PWDs was reduced and they take themselves in positive way with enhanced self esteem.

9.58% of PWDs responded that due to negative, humiliating remarks and unequal treatment by others they felt offended. But after SPARC-India's intervention the respondents, stated that earlier they used to hesitate and were not comfortable in interacting in social gatherings, but after SPARC-India's involvement, responses were very much positive and remarkable. 23.36% of respondents stated that at present they feel positive, confident, participates in social gathering with confidence due to support from the society and individuals.

34.93% of respondents showed negative feeling. They responded that they feel alone, sad and segregated from others. In pre intervention phase they stated that they were not sure about their future and lots of apprehensions were attached to their thoughts. When some questions were raised in post intervention phase they stated that, now they feel independent, confident and take life positively with 33.64%.

2. PERCEPTION OF SELF IN RELATION TO OTHERS: THEN AND NOW

In order to collect information on perception of the PWDs by others, the question asked was as follows: "दूसरे लोगों के साथ तब कैसा महसूस करते थे और अब कैसा महसूस करते हैं?"

Largely, there were four categories of responses that emerged while taking note of perception of PWDs in relation to others, the categories are listed below:

- Attitude of others
- Comfort level
- Equality in treatment

The table below illustrates the distribution of the responses for the two points of time:

Table. 3.2 : Perception of self in relation to others for the pre & post intervention on inclusion

Categories	Typical examples of responses	
	Pre-Intervention	**Post-Intervention**
Attitude of others	• गांव व पास–पड़ोस के लोग मुझे अलग समझते थे उनका व्यवहार हमारे प्रति नकारात्मक था बातचीत व्यवहारिक जीवन में काफी फर्क महसूस होता था। • दूसरे लोगों के साथ मैं बैठना उठना पसन्द नहीं करती थी क्योंकि लोगों की सोच मेरी प्रति ठीक नहीं थी, लोग मुझे घृणा से देखते थे।	• गांव के लोगों का घर के लोगों का व्यवहारात्मक सम्बन्धों में काफी परिवर्तन हुआ है। • अब मैं यही महसूस करती हूं कि लोग मुझे ठीक तरह से बुलाते हैं, और मुझसे बाते भी करते हैं मैं उनके साथ बातचीत करके काफी खुश होती हूं।
Comfort level	• तब मैं दूसरे लोगों के साथ में यही महसूस करता था, कि सामान्य लोग विकलांग लोगों से इतना क्यों नहीं व्यवहार करते हैं। जिससे विकलांग व्यक्ति भी सामान्य व्यक्ति बन सके। • दूसरे लोगों के साथ उठना बैठना नहीं अच्छा लगता था। वे नाम लेकर नहीं पुकारते थे।	• अब मैं स्वयं सामान्य व्यक्ति की भांति रहता हूँ और सांस्कृतिक तथा सामुदायिक कार्यों में भागीदारी करता हूँ। • अब अच्छा महसूस करते हैं। वे अब नाम लेकर पुकारते हैं।
Equality in treatment	• समाज में लोगों को हमारे प्रति एक अलग धारणा थी जिसमें हमें बराबरी का दर्जा नहीं मिल पाता था। • मैं दूसरे लोगों के साथ अपनी विकलांगता के कारण उनके पास उठता–बैठता नहीं था, क्योंकि लोग मुझे लगड़ा कहते थे।	• लोग अब सम्मानजनक व्यवहार करते हैं और फर्क नजर नहीं आता है। • मैं दूसरे लोगों के पास में जरूर–जरूर बैठता हूं क्योंकि मैं भी समाज का एक अंग हूं। लोगों के गलत दृष्टिकोण मेरे प्रति अब काफी अच्छा हुआ है।

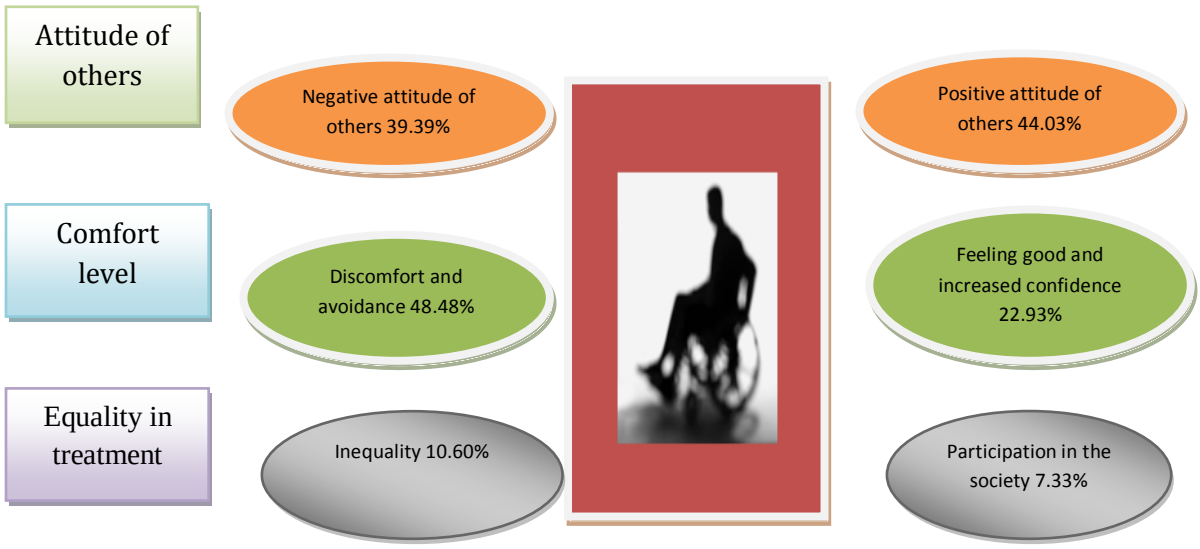


Fig. 3.2 : Perception of self in relation to others for the pre & post intervention on inclusion

There was a vital change noticed in the perception of self of the PWDs in relation to others and also there was found an improvement in their comfort level with others and awareness about self and disability. Before the intervention project conducted by the organization in the Deva block there were around 39.39% of responses showed that the community had negative attitude towards the PWDs and there was a lot of name calling and teasing that the PWDs had to face. However, after the intervention project by SPARC-India, in all 44.03% responses reflected that there was a positive change in the community members towards the PWDs and that the PWDs reported that they were now helped whenever needed and are treated with love and respect.

There were 41.67% of responses of PWDs who stated feeling hopeless, dependent and inferior to others before the interventions done

by the organization. They used to live alone and did not enjoy interacting with others especially non-challenged people due to their feeling of inferiority in them. Nevertheless, the intervention project was successful in transforming 22.93% of responses on positive note, wherein the PWDs acknowledged the work done by the organization and said that they feel positive about self, are more confident in life and are no more hesitant in taking initiatives.

Prior to the intervention project carried out in Deva block ***the rate of awareness on disability was very low*** amongst the PWDs **(1.52%),** which **after the intervention efforts by the organization has increased to 25.69%.** Also, there was a lot of inequality and discrimination by the community towards the PWDs, around 10.61% responses revealed that the social treatment of PWDs was very biased and unequal to others. On the other hand, the positive efforts of SPARC-India were able to alter this percentage to 7.34%, wherein the responses reflected that the PWDs have started participating in the social activities like a non-challenged person and feel a part of the society.

3. BEHAVIOUR OF OTHERS TOWARDS PWDS: THEN & NOW

In order to collect information on perception of the PWDs by others, the question asked was as follows: "आपके साथ लोगों को व्यवहार तब कैसा था और अब कैसा है".

Largely, there were three categories of responses that emerged out while taking note of behaviour of others towards PWDs, the categories are listed below:

- Mindset & Awareness
- Compassionate & Sympathetic
- Discriminatory behaviour

The table below illustrates the distribution of the responses for the two points of time.

Table-3.3 : Behavior of others towards PWDs pre & post intervention on inclusion

Categories	***Typical examples of responses***	
	Pre-Intervention	***Post-Intervention***
Mindset & Awareness	• लोगों का व्यवहार अच्छा नहीं था। वे सोचते थे विकलांग होने से कुछ नहीं कर सकता है। • उनकी सोच हम लोगों के प्रति नकारात्मक है। • इसलिए लोगों का व्यवहार अच्छा नहीं था। माता पिता भी शादी उत्सव में नहीं ले जाते थे।	• सामाजिक क्षेत्र में मुझे सम्मान और बराबरी की नजर से देखते हैं। गांव के माहोल में बदलाव हुआ है। अबशब्दों से पुकारने की प्रथा समाप्त हुई है। • अब जागरूक हो गये हैं। हमारे कामों में मदद करते हैं। शादी उत्सव में सहेली के साथ स्वयं चली जाती हूं।
Compassionate & Sympathetic	• लोगों को मेरे प्रति हीनभावना दया जैसा एवं समाज में अलग की भावना थी। • लोगों का व्यवहार अच्छा नहीं था। वे अपने साथ कहीं नहीं ले जाते थे। अगर साथ ले भी गये तब वे वही छोड़कर आगे–आगे चले आते थे।	• समाज में सहभागिता बढ़ी है, लोग सामाजिक व्यवहार करते हैं। • अब जागरूक हो गये हैं। वे अपने साथ लेते और ले जाते हैं। काम में मदद करते हैं।
Discriminatory behaviour	• लोग गलत व्यवहार करते थे, जिससे मुझे ज्यादा मन, उनके पास जाने में नहीं लगता था।	• मैं अधिकतर अब सामाजिक लोगों से जुड़ा हूं और उनकों बातचीत से समस्या का हल भी निकालता हूं। • अब पढ़ लिख गया हूं। पेन्शन मिलती है। ट्राई साइकिल से बाजार से सामान लेता हूं। स्वयं अपना काम करता हूं। इस कारण गांव के लोग मदद करते हैं। अब उनमें परिवर्तन भी आया है।

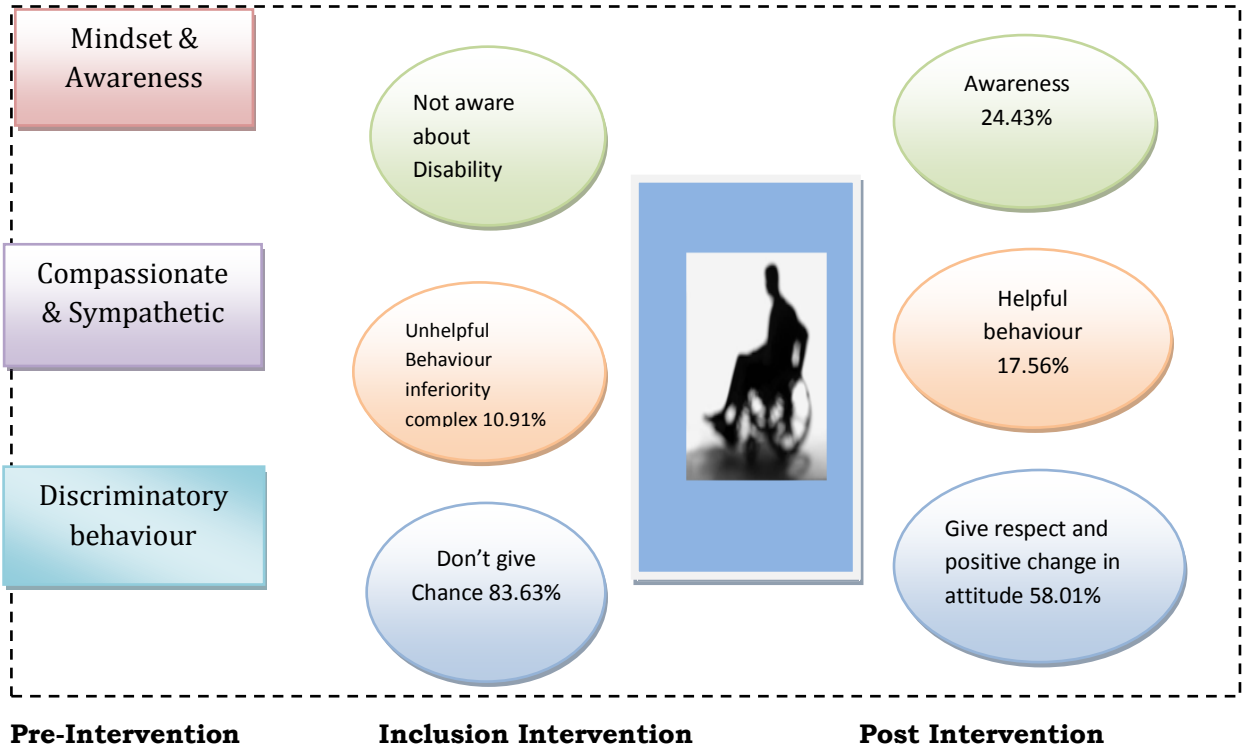


Fig. 3.3 : Behavior of others towards PWDs pre & post intervention on inclusion.

The typical responses and the distribution of the data clearly show a change in the mindset along with a positive increase in the awareness level from 5.45% to 24.43%.

24.43% respondents stated that the people in community are more aware about their disability, as well as, their rights and do not treat them as inferior. The negative mindset of rejection and discount has also given way to community participation.

Fig. 3.3 also shows that only 10.91% respondents stated that they got help if and when needed from others. However, rest of the respondents gave a negative reply to the question asked. This also shows that a large no. of people from our society are not sensitive towards the

PWDs and the challenges faced by them and are hence, do not come forward for their support.

This support has also improved to 17.56% and they felt as a part of the community with the same needs and rights. This indicates that the sensitization work done by the organization for the local community people.

83.63% respondents mentioned that before the intervention program done by SPARC-India they experienced discrimination and rejection from the society as well as their own family members and relatives. Society did not accept persons with disabilities and get biased and judged them on the basis of their disability and did not give them a chance to grow, to do something in their lives as per their wish. But after the intervention of SPARC-India 58.01% respondents stated that they noticed positive change now in their family members, society and other people accept them with respect and dignity they also give them space to share their views.

4. ATTITUDE TOWARDS LIFE: THEN AND NOW

In order to collect information on perception of the PWDs by others, the question asked was as follows: "**जिन्दगी के प्रति आपका नजरिया तब कैसा था अब कैसा है।**"

Largely, there were these categories of responses that emerged out while taking note of attitude towards life, the categories are listed below:

- Worth of life
- Perspective in terms of Hope
- Meaning of life

The table below illustrates the distribution of the responses for the two points of time.

Table-3.4 : Attitude towards life pre & post intervention on inclusion

Categories	Typical examples of responses	
	Pre-Intervention	**Post-Intervention**
Worth of life	• विकलांगता की समस्या होने के कारण मैं सेहत की भी समस्या से परेशान था और मैं इस समस्या के बारे में हमेशा सोचता रहता था। • जिन्दगी के प्रति मैं स्वयं भी जिन्दगी को बोझ समझता था, कि हम कुछ भी नहीं कर सकते हैं। यह मुझे हमेशा एहसास हो रहा था कि मेरे सिवाय दूसरा कोई ऐसा नहीं है।	• मेरी जिन्दगी अमूल्य है। मैं जो भी हूँ अच्छा हूँ। आत्मनिर्भर होना चाहता हूँ। • संस्था में जुड़ने से मुझे लगा कि जीवन जो भी है ठीक है और बोझ नहीं है और समाज में ऐसे कार्य हैं जिनको हम भी सरलता से कर सकते हैं।
Perspective in terms of Hope	• बहुत दुःख महसूस होता था कि कैसे जीवन चलेगा और हरपल अंधेरा दिखाई देता था। • जिन्दगी में अकेलापन था और जीवन के प्रति निराशा थी। • जिन्दगी के प्रति कुछ नया सोचने के अवसर नहीं थे। गांव में रहकर बड़ी उदासी और मायूसी थी। • जिन्दगी में मायूसी नजर आती थी और हम समझते थे कि यह जीवन बेकार है। कुछ समझ में नहीं आता था।	• कुछ बदलाव मालूम होता है। क्योंकि गांव के लोग महिलाएं अब सम्मान की नजर से देखते हैं। • मेरा जीवन लम्बा हों और मैं कुछ कर सकूं। • मुझे खुद संस्था से अपने एवं समाज के लिए कुछ कर दिखाने का अवसर प्रदान हुआ। इससे मेरी जिन्दगी ने एक नया मोड़ लिया। • अब नई राह में जीवन जीना चाहते है। कुछ पाने की आशायें बढ़ी है और इच्छा शक्ति भी बढ़ी है।
Meaning of life	• मेरे लिए जिन्दगी का कोई मूल्य नहीं था, मैं स्वयं को कुछ न कर पाने लायक सोचता था। • जिन्दगी के प्रति मेरा यही नजरिया था कि मेरी जिन्दगी बेकार है। मैं कुछ अच्छा काम नहीं कर सकता	• मेरी जिन्दगी अमूल्य है। मैं जो भी हूँ अच्छा हूँ। आत्मनिर्भर होना चाहता हूँ। • सामान्य लोगों की भांति मेरी जिन्दगी है। मैं भी सब काम कर सकता हूं।

	ह्यं।	

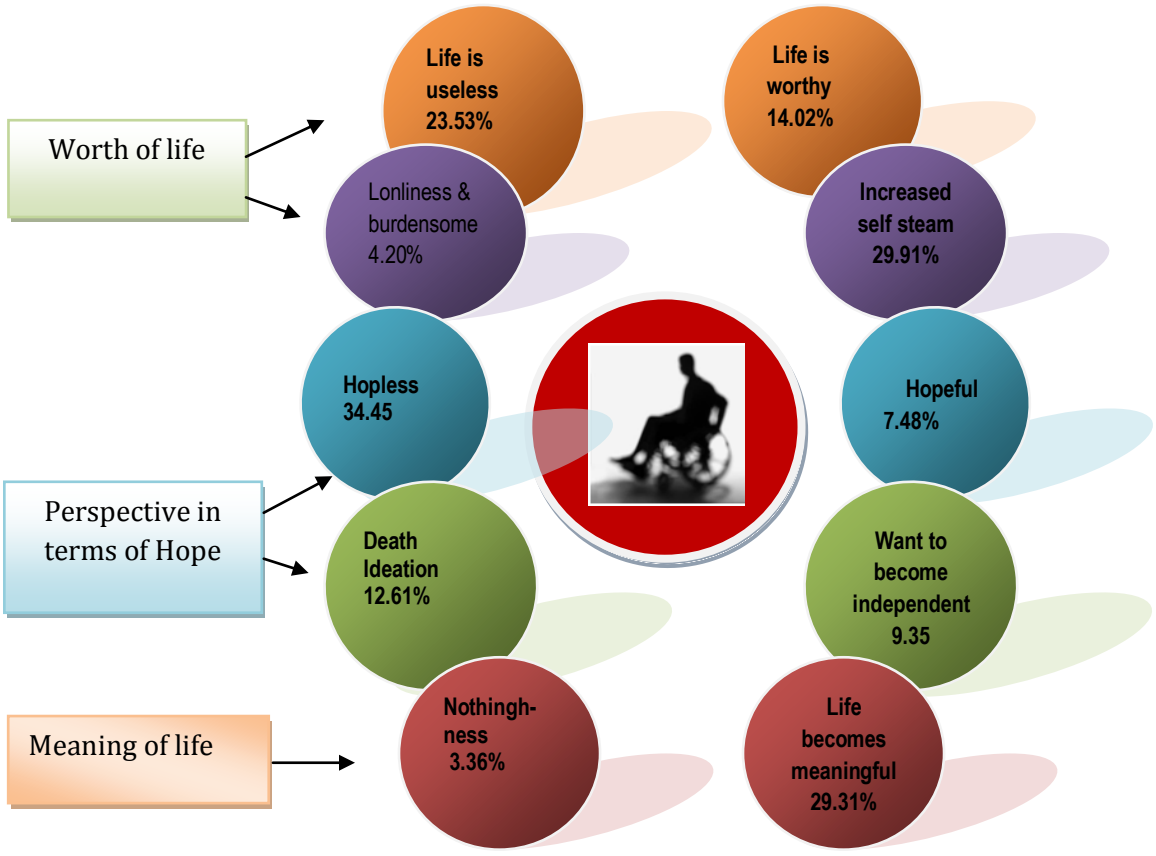


Fig. 3.4 : Attitude towards life pre & post intervention on inclusion

There is a significant change in the attitude of PWDs towards their lives since the intervention made by SPARC India. A major observation of their responses was that they had a very pessimistic and negative attitude towards their lives **before** the intervention program was carried out by the organization. 34.45% of the respondents mentioned

that they felt very hopeless in life and had no expectation of any good from their life. Out of the total responses, around 23.53% respondents replied that they felt their life was useless. 12.61% of the respondents mentioned that "they think about suicide sometimes". Many other respondents clearly stated their feeling of hopelessness, loneliness with 4.20%, nothingness in life and feeling their life as a burden to them around 3.36%, which clearly shows the gloomy attitude of PWDs towards their life.

On the other hand, after the intervention there was a noteworthy change in the attitude of PWDs towards their lives as 29.91% of the respondents replied that their self esteem and self confidence has increased, 29.31% of the respondents mentioned that their life became meaningful, 14.02% mentioned that they feel that their life is worthy, 7.48% PWDs feel hopeful about life, 9.35% PWDs replied that they want to become independent since they had been in touch with SPARC-India.

5. PERCEPTION ABOUT HEALTH AND HEALTH RELATED PROBLEMS: THEN AND NOW

In order to collect information on perception of the PWDs by others, the question asked was as follows: "सेहत और सेहत से जुड़ी अपनी समस्या के लिए आप तब क्या सोचते थे और महसूस करते थे और आज क्या सोचते और महसूस करते हैं?

Largely, there were these categories of responses that emerged out while taking note of perception about health and health related problems, the categories are listed below:

- Awareness about health
- Importance of health

- Anxiety and stress related to health

The table below illustrates the distribution of the responses for the two points of time.

Table - 3.5 : Perception about health and health related problems pre & post intervention on inclusion

Categories	Typical examples of responses	
	Pre-Intervention	**Post-Intervention**
Awareness about health	• मुझे खुद के स्वास्थ्य के विषय में इतनी जानकारी नहीं थी। लेकिन जागरूकता का भी अभाव था अपने स्वास्थ्य के विषय में कुछ नहीं करते थे। • सेहत और सेहत से जुड़ी अपनी समस्या के बारे में तब मैं यही सोचता था कि मैं कुछ काम भी नही करता हूँ। शरीर भी ठीक–ठाक नहीं है और मुझे काफी चिन्ता थी जिससे सेहत के प्रति जुड़ी समस्या थी।	• खुद के विषय में मैं आज अच्छी तरह से अपने स्वास्थ्य का ख्याल रख सकता हूं। • आज मैं अपनी सेहत से जुड़ी समस्या के बारे में सोचता हूं कि जागरूकता ही समस्या का निवारण है।
Attitude towards Personal Health	• सेहत और सेहत से जुड़ी समस्या के बारे में तब मैं यही सोचता था कि मुझे जीवन के प्रति काफी निराशा है। मैं अपने स्वास्थ्य के प्रति भी काफी ध्यान नहीं देता था। • सेहत से जुड़ी अपनी समस्या के लिए तब मैं अपने सेहत के बारे में ज्यादा ध्यान नहीं देता था, मैं यही समझता था कि जीवन बेकार है, सेहत से क्या फायदा!	• आज मैं अपनी सेहत से जुड़ी समस्या के प्रति अब यही सोचता और महसूस करता हूँ कि अगर जीवन में स्वास्थ्य के प्रति जानकारी हो तो सेहत से जुड़ी समस्या अच्छी हो सकती है। • आज मैं अपनी सेहत से जुड़ी समस्या के प्रति काफी ध्यान दे रहा हूं कि सेहत के लिए अच्छी जानकारियां होनी चाहिए।
Health status and mindset about	• मैं हमेशा बीमार रहता था। क्योंकि मुझे बोन टी0वी0 था अपने स्वास्थ्य के प्रति सचेत नहीं था। क्योंकि गरीबी और	• संस्था का मेरे प्रति बहुत बड़ा सहयोग और मार्गदर्शन रहा। क्योंकि संस्था के सहयोग से मेरे शरीर का

health	अज्ञानता के कारण ठीक से इलाज नहीं हो पा रहा था। • सेहत से जुड़ी अपनी समस्या के प्रति मैं यही सोचता था कि मेरा जीवन कैसे चलेगा, मैं हमेशा सेहत के लिए ध्यान नहीं देता था।	इलाज हुआ और मैं ठीक हो गया। अब उन्हीं के बताये रास्तों पर मैं चलता हूँ। इसलिए मैं अच्छी तरह से अपने स्वास्थ्य का ध्यान रखता हूँ। • आज सेहत से जुड़ी समस्या के प्रति मैं यही सोचता हूं कि अगर हम लोगों को ट्रेनिंग दी जाए तो सेहत के प्रति काफी ध्यान रहे और जुड़ी समस्या भी दूर हो जाए।

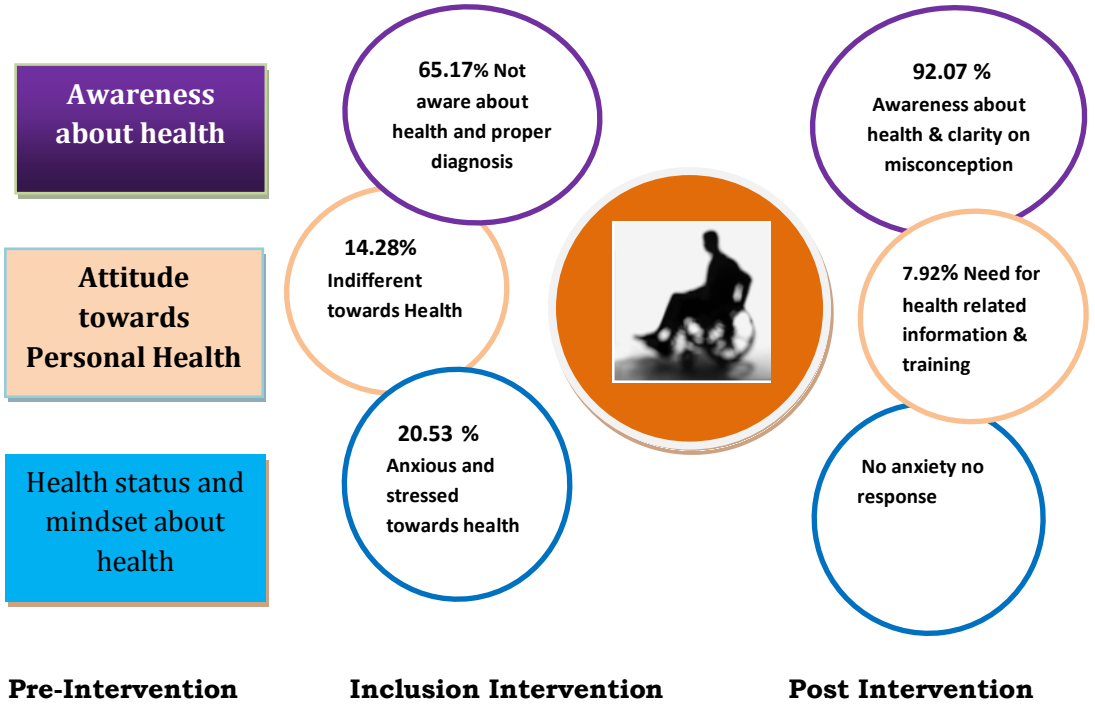


Fig. 3.5 : Perception about health and health related problems pre & post intervention on inclusion

A significant change is noticed in the PWDs perception of health and their health related problems since the intervention made by SPARC-India. 65.17% respondents mentioned that they were not aware about their own health related problems, its causes and its proper diagnosis. However, after the inclusion intervention project carried out by the

organization, there were about 92.07% respondents who stated that they were now aware of the misconceptions prevailing about their health. There were 14.28% respondents stating that initially they were not so much alert of their health and remained indifferent towards their health but eventually after the intervention, they understood the need for health related information and training for the PWDs. Moreover, there were 20.53% respondents who stated feeling very anxious and stressed due to their health concerns but after the intervention there were no anxiety and stress responses given by the PWDs.

6. BENEFITS FROM THE PROGRAM: THEN AND NOW

In order to collect information on perception of the PWDs by others, the question asked was as follows: "**इस परियोजना में शामिल होने से क्या आपको कुछ लाभ हुआ?**"

Largely, there were these categories of responses that emerged out while taking note of benefits from the program, the categories are listed below:

- Awareness about Laws acts and rights
- Medical Treatment
- Increased awareness about disability In own self and community
- Getting govt. facilities with the help of SPARC-India

The table below illustrates the distribution of the responses for the two points of time:

Table-3.6 : Benefits from the program pre & post intervention on inclusion

Categories	Post-Intervention
Awareness about Laws acts and rights	• संस्था के सहयोग से सर्वप्रथम विकलांगता कानून व अधिनियम, बस, पास, प्रमाण पत्र तथा संगठन से जुड़ाव। • मुझे परियोजना से काफी कुछ सीखने को मिला जैसे कि शिक्षा, आरक्षण कानून, विकलांगता प्रमाण पत्र, बस पास आदि के विषय में जानकारी प्राप्त हुई।
Medical	• परियोजना में शामिल होने से मुझे चलने–फिरने के लिए साइकिल

Treatment	मिली है, जिससे मैं इधर–उधर चल फिर सकती हूं। • मुझे समय पर उपकरण (ट्रा0 सा0) उपलब्ध हो जाती है। अवागमन सुविधा हुई है। प्रमाण पत्र पेंशन लाभ मिला आवास का भी सहयोग मिला।
Increased awareness about disability In own self and community	• ग्राम पंचायत स्तर पर विकलांग जनों क्या अधिकार है। इन्दिरा आवास पट्टा भूमि पेंशन खुली बैठक आदि के बारे में जानकारी प्राप्त हुई है। • सर्वप्रथम मेरी पेंशन बनी जिससे मैनें अपना खर्च चलाना शुरू किया और विकलांग लोगों के अधिकारों के विषय में पता चला।
Getting govt. facilities with the help of SPARC-India	• मुझे काफी सहायता मिली, जैसे आवागमन सुविधा, बस रेल, पास, पेंशन आदि लाभ मिला है। • मुझे सरकारी योजनाओं के बारे में जानकारी तथा घर से ब्लॉक एवं पंचायत की बैठकों के बारे में जानकारी व संस्था के कार्यक्रम भी रूचिदार लगे।

Fig. 3.6 : Benefits from the program pre & post intervention on inclusion

Altogether the respondents gave a very positive response towards the benefits received from the program. It was found that all the beneficiaries, in some or the other way were benefitted and supported by the inclusion program carried out by SPARC-India. 56.83% of PWDs mentioned of availing various government facilities with the help and support of SPARC-India. The above figure clearly reflects that around 20% beneficiaries were more aware about their rights, entitlements and

laws made for them, also, they were found to be more aware about their disability, its causes and consequences, by the end of the project.

7. CHANGE FELT AFTER JOINING SPARC-India

In order to collect information on perception of the PWDs by others, the question asked was as follows: "**स्पार्क इंडिया से जुड़ाव के बाद से क्या आपने खुद में कोई तब्दीली/परिवर्तन महसूस किया है ?**

Largely, there were these categories of responses that emerged viz.:

- Increased participation in social activity
- Independence & self reliance
- Positive changes in life

- Feeling of being equal to others
- Increased Knowledge
- Awareness about rights of PWDs

The table below illustrates the distribution of the responses for the two points of time:

Table-3.7 : Felt changes after joining SPARC-India Project of Inclusion

Categories	Post-Intervention
Increased participation in social activity	• अपने अधिकारों के प्रति स्वयं जागरूक हुआ हूं और सामाजिक कार्यों में भागीदारी बढ़ी है। सम्मान के दृष्टिकोण से लोग देखते हैं। • स्पार्क इण्डिया से जुड़ाव के बाद मैनें स्वयं में एक सम्मान जीवन जीने का परिवर्तन महसूस किया है।
Become Independent	• जुड़ाव के बाद से मैनें नकारात्मक विचारों से साकारात्मक विचारों को महसूस किया है और स्वयं आत्मनिर्भर हुआ हूँ।
Positive changes in life	• जुड़ाव के बाद मेरे जीवन में एक नई उमंग आयी है और काफी बदलाव भी आया है, मैं विकलांगता को कोई समस्या नहीं मानता हूँ। • जुड़ाव के बाद में मैनें एक अलग बनाई है। अपने जीवन में बदलाव लाकर क्षेत्र के विकलांगजनों की समस्या को हल करना चाहता हूँ।
Equality in society	• विकलांग जनों को समाज में बराबर का दर्जा मिला है। सामान्य व्यक्तियों की तरह ही उनको अधिकार अवसर दिये गये हैं। • सामाजिक कार्यों में भागीदारी बढ़ी है। सम्मान के दृष्टिकोण से

	लोग देखते हैं। • अब संस्था के कार्यों से ज्ञात होता है कि समाज में विकलांग जनों का बराबर का दर्जा दिया जा रहा है।
Increased Knowledge	• मुझे विभिन्न प्रकार की जानकारी मिली कि विकलांग जनों को भी समाज में बराबर का अधिकार है। उन्हें समाज से अलग न समझा जाये। संस्था के माध्यम से सरकार द्वारा मिल रहे लाभों को प्राप्त करने में अपनी भागेदारी निभाई, पेंशन उपकरण यातायात में छूट, आवास भी प्राप्त करने में लाभ मिला। • मेरे अन्दर पढ़ने की इच्छा बिल्कुल नहीं थी। इच्छा टूट चुकी थी। लेकिन ट्रेनिंग प्रशिक्षण से मुझे लगा शिक्षा भी जीवन का एक महत्वपूर्ण अंग हैं। आज मैनें उन्हीं के बतावे अनुसार बी0ए0 पास किया है।
Awareness about rights of PWDs	• अपने अधिकारों के प्रति स्वयं जागरूक हुआ हूं • विभिन्न प्रकार की जानकारी हुई। विकलांग जनों को बराबर का अधिकार है। • तरह–तरह की जानकारी मिली है। विकलांग जनों को समाज में बराबरी का दर्जा मिला है।

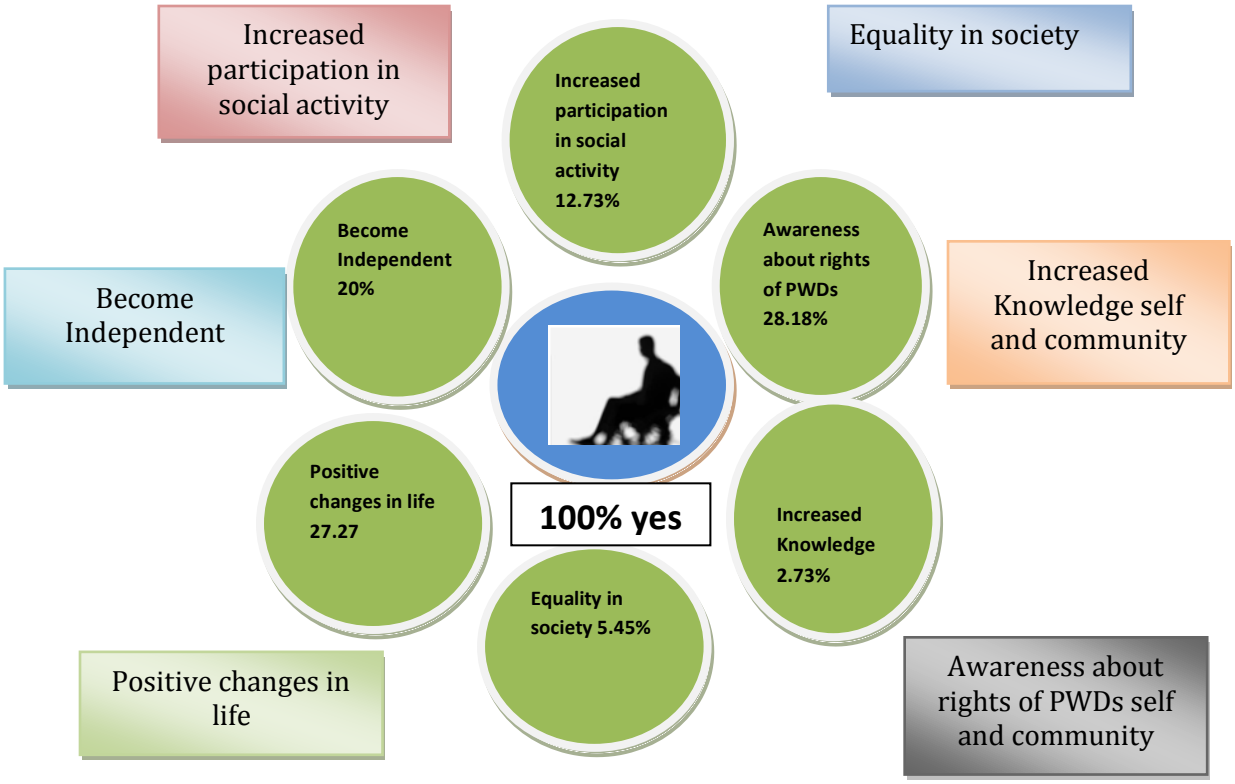


Fig. 3.7 : Felt changes after joining SPARC-India Project of Inclusion

There was a noteworthy change in all the beneficiaries after joining hands with SPARC-India. The PWDs reported feeling positive. They also felt independent after being associated with the project due to their increased knowledge and awareness gained the initiative of inclusion by 20%.

27.27% of the responses reflected that they had not only started feeling good about themselves but also were viewing the world with a positive lens. Out of the total respondents, around 28.18% of the beneficiaries reported of becoming more aware of their rights and being able to exercise them and participating equally in the society. The beneficiaries felt these changes in themselves as a result of their increased knowledge and awareness.

All the dimensions clearly reflect that the beneficiaries had a positive view towards themselves and their lives after the intervention project was carried out by SPARC-India. This supports the assumption that "there would be a positive change in the perception of self and the world view after the intervention project on inclusion."

PHASE B. HEALTH PERCEPTIONS, MENTAL HEALTH STATUS, AND SELF OTHER RELATEDNESS

Since this section addresses both health perceptions and health status, the results of the same would be discussed under three sections, viz.

Section B.I: Health Perceptions, Section B.II: Mental Health Status and Section B.III: Self Other Relatedness

Section B.I: HEALTH PERCEPTIONS

Since awareness is at the realm of all perceptions, health awareness is being taken as the core of the various aspects of health perceptions. Four major dimensions of health perceptions are taken in the schedule are as follows:

B.I. (i) Health Awareness

B.I. (ii) Mental Health Perceptions

B.I (iii) Perception of Disability

B.I (iv) Substance Dependence

B.I. (i) Health Awareness:

Awareness implies the building up of knowledge and capability for reasoning based on logical facts rather than affective factors. The capacity to reason depends upon the extent and accuracy of the information flow from different sources associated with certain amount of authenticity to improve the credibility of information and its acceptance. **Bharat (2002) contends in her study that knowledge and awareness about health related problem in communities was at a very basic level. Such a finding suggests that individual responses to illness are shaped by their perception and meaning associated with illness.** This statement reflects that communities by and large in developing countries have very elementary knowledge of health related issues, which are influenced by deep rooted perceptions & thoughts of people. **Fig 3.8 spells out the eight dimensions of health awareness in the present study**.

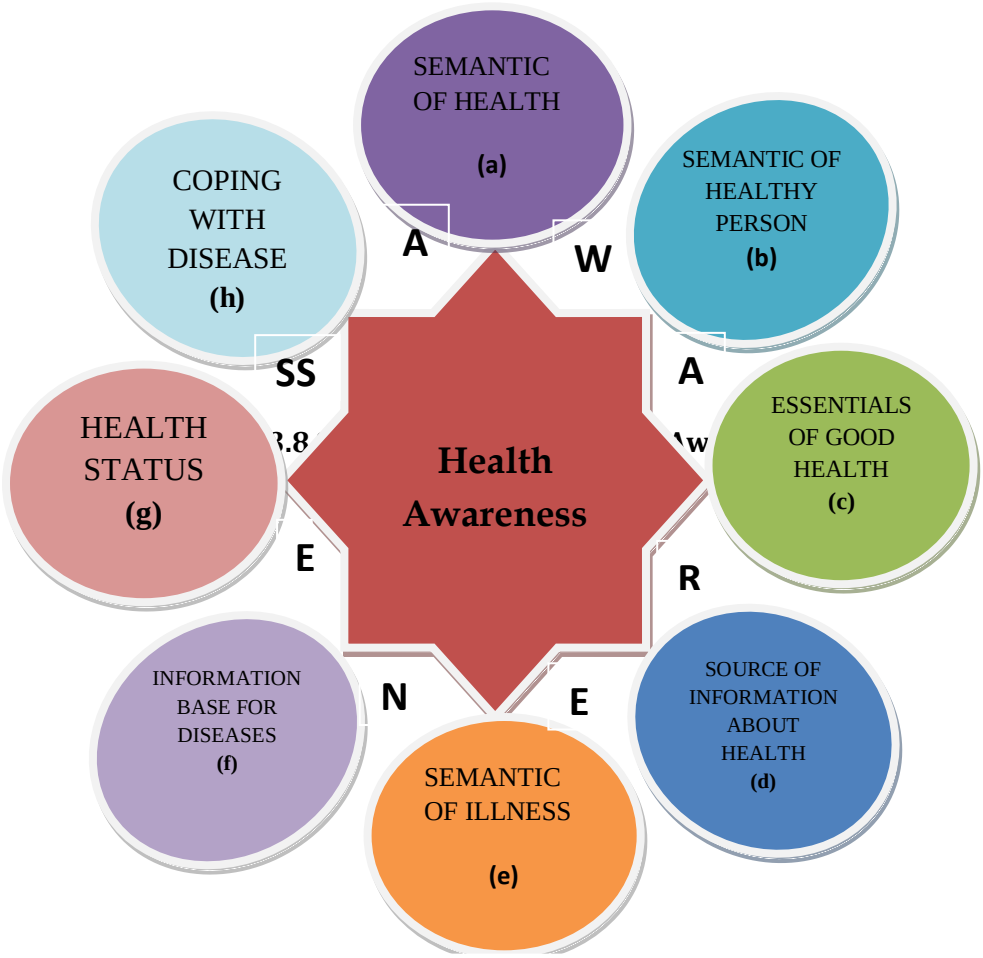


Fig. 3.8 Sub Dimensions of Health Awareness

Each of the dimension is being taken up separately.

(a) **Sementic of Health**: Our bodies are made of experience transformed into physical expression. The cells are continuously processing experience and metabolizing the same. The mind influences every cell in body and biochemistry of the body is a product of awareness. Being healthy is again a choice that inculcates not only healthy habits but also positive coping and effective management of crisis at physical or mental level. Above all the extent to which we are aware of this state decide how healthy we would be. Hence, the first question addressed the issue of how

the people of Deva block construe health. The question asked was **"सेहत से आप क्या समझते है।"**

The data when content analyzed generated seven major response categories : (i) Absence of illness and physical pain (ii) Work efficiency (iii) Robust body and strength (iv) Healthy Habits (v) Synonyms (vi) Redundant (vii) Do not Know.

Table - 3.8 : SEMANTIC OF HEALTH ACCORDING TO CHALLENGE STATUS

S. No	Categories	a1	a2	Total	CR
		P.W.D	Guardian		
		%	%		
1	Absence of illness and physical pain	32.99	24.42	28.96	1.49
2	Work efficiency	10.31	15.12	12.57	0.98
3	Robust body and strength	14.43	23.26	18.58	1.51
4	Healthy Habits	4.12	17.44	10.38	2.95**
5	Synonyms	5.15	11.63	8.20	1.59
6	Redundant	31.96	4.65	19.13	4.68**
7	Do not Know	1.03	3.49	2.19	1.13

Table 3.8 reflects seven major response categories and among the seven categories, it was the category of **'Absence of illness'which emerges predominantly as the perceived meaning of health with 28.96% response "**जौन बीमार ना हो और कौनो दर्द ना हो।**"**

An important finding here was that almost **21% of subjects do not have awareness for the concept of health** as evident from the categories of '**Redundant'** and '**do not know'** (19.13 and 2.19 respectively). Interestingly it was more of a1 which has lesser awareness than their caregivers (a2).

With reference to challenge status, both a1and a2 predominantly conceive '**Absence of illnesses** as health. However, the interesting difference between the perception of PWDs and caregivers were that the former had more of '**Redundant'** response (31.96%) in comparison to PWDs (4.65%) with C.R. 4.68<0.01. The caregivers had the traditional conception of health in '**Robust body and strength'** (23.26%) in comparison to 14.43% of a1 '**Healthy habits'** was a positive connotation of health employed more PWDs and caregivers and this was a positive finding **(C.R.2.95<0.01)**.

Tilak (2002) in her study on slum dwellers reported that only 37% of the sample conceived health as good physical appearance. Similar findings were obtained in the perception of women farm labor (Pandey, 2006). Though in the latter study, response categories of lack of disease and physical fitness also emerged in his study on villagers of Deva block found that 38.39% of them said they did not know the meaning of health lending support to the present findings.

(b) Semantic of Healthy Persons

The body is the material result of all the intentions one has ever had. Thus, it is the holistic view and the attitude one has towards life, which decides whether the person would be healthy or unhealthy. The question asked was **"सेहतमदं आदमी कैसा होता है।"**

This question generated huge amount of data which when content analyzed brought forth eight major categories. They are- *'Hard Working & Efficient', 'Good & Healthy to Look at', 'Good habits and happy', 'Redundant', 'Do not Know'.*

Table - 3.9 : HEALTHY PERSON ACCORDING TO CHALLENGE STATUS

S.No	Categories	a1	a2	Total	CR

		P.W.D %	Guardian %		
1	Hard Working & Efficient	36.5	36.45	36.48	
2	Good & Healthy to Look	39.42	25.23	33.20	2.04*
3	Good habits and happy	16.06	24.3	19.67	1.39
4	Redundant	5.84	9.35	7.38	
5	Do not Know	2.19	4.67	3.28	

As is apparent from table 3.9, the data seems to be distributed across all categories although it is the category of **'Hard Working & Efficient'** which has maximum number of responses (36.48%) with response like **"जो अपना काम करने मे थके नहीं।"**

With reference to challenged status, the result appear rather interesting, Persons with disabilities (PWD_s) tend to report **'Good & Healthy to look'** as their perception of a healthy person (39.42%) in comparison to caregivers where 25.32% feel this way (CR=2.04<0.05) with response like. **"तगड़ा तंदुरूस्त होता है, आदमी तो अच्छा लगता है।"**

Good physique and physical appearance strongly emerge as the predominant meaning of good health in villagers of Katra and a village in Raibareilly (Kumar 2005 and Panday 2006) Tilak (2002) in her study on slum dwellers reported that only 37% of the sample conceived health as good physical appearance. Similar findings were obtained in the perception of women farm labor (Pandey, 2006). Though in the latter study, response categories of lack of disease and physical fitness also emerged.

B.I (i) (c) : Essentials of Good Health

What health is for one may not be the construed meaning for other. Similarly, the importance of good health may vary for people. This

question explores the perceptual beliefs, as well as, the information base of people's health. The question asked was- **"अच्दी सेहत के लिये क्या जरूरी है।"**

As is evident from the question, it explores the prerequisites of health. The voluminous data was content analyzed. Five response categories emerged out of the data. They are: **'Good and Nutrition Diet', 'Exercise and Walk', 'Healthy Food Habits', 'Hygiene' and 'Redundant'.**

Table-3.10: ESSENTIALS OF GOOD HEATH ACCORDING TO CHALLENGE STATUS

S. No.	Categories	P.W.D Freq	Guardian Freq	Total	a1 P.W.D %	a2 Guar dian %	Total	CR
1	Good and nutrition diet	61.0	70.0	131.00	48.41	72.92	59.01	3.37**
2	Exercise and walk	22.0	6.0	28.00	17.46	6.25	12.61	7.23**
3	Healthy food habits	20.0	14.0	34.00	15.87	14.60	15.32	
4	Hygiene	22.0	5.0	27.00	17.46	5.21	12.16	2.57*
5	Redundant	1.0	1.0	2.00	0.79	1.04	0.90	
	Total	126.0	96.0	222	100.00	100.00	100.00	

As it is evident from table 3.10, it was the category of **'Good & Nutritious Diet' (59.01%)** which covers the major part of the response distribution and more of a_2 conceive **'Good & Nutritious diet'** a_1 **(a_2=72.g2, =a_1=48.1, C.R. =3.37< 0.01)** with response like. **"अच्छा खाना, दाल, सब्जी, दूध, घी, पौष्टिक आहार ".** Another finding was that more of PWDs conceive correlates of health in terms of **'Exercise and Walk'** in comparison to their counterparts **(a_1 =17.46, a_2 =6.25, C.R=7.23<0.01)** with response like **"अच्छी हवा मे घूमना कसरत करना।".** It was worth mentioning here more of PWDs believed hygiene to be correlate of health, an caregivers **(17.46% & 5.21% respectively, C.R = 2.57<0.05)** with response like **"साफ सुधरा खाना खाना चाहिये घर के आस पास सफाई का ध्यान रखना**

चाहिये।" .More of a_1 are aware of the importance of healthy food habits in comparison to a_2.

The finding of Kumar(2005),Tilak(2002), and Panday(2006) also lend support to the result where good diet has been predominantly perceived as the essential of good health.

B.I. (i)(d) Sources of Information about Health

Our bodies are the physical results of all the interpretation we have been learning to make since we were born. To what extent does one care for her health also depends on the information base or awareness about her health hence it was felt necessary to explore the information base of health in the inhabitants of Deva Block. **The question asked was "सेहत के बारे में जानकारी आपको कहॉ से मिलती है।"**

Five major categories emerged; they are, **'Doctor, Primary Health Center', 'People, Community, Panchayat etc', 'Books, T.V., Radio, Newspaper', 'SPARC- INDIA' and 'Family'.**

S. No	Categories	P.W.D(al) %	Guardian(a2) %	Total	CR
1	Doctor & primary health center,	36.92	49.51	42.49	1.7
2	People, community, Panchayat etc.	15.38	12.62	14.16	
3	Books, TV, Radio, Newspaper	16.15	7.77	12.45	1.72
4	SPARC INDIA	10.77	7.77	9.44	
5	Family	20.77	22.33	21.46	

Table-3.11: SOURCE OF INFORMATION ABOUT HEALTH ACCORDING TO CHALLENGE STATUS

As is clear from the table 3.11 most of the respondents **(42.49%)** said "**Doctor & Primary health centre"** This appears predominantly as the source of information about health. **"सरकारी अस्पताल और गॉव के डाक्टर से जानकारी मिलती हैं।"**

B.I.(i)(e) Semantic of Illness

How one addresses and copes up with illness is to a large extent dependent upon the perceived meaning of disease. The question asked was. **"बीमारी क्या होती है।".** This question explores semantic of disease. A wide variety of data is generated which after content analysis brought forth six major categories.

Table- 3.12 : SEMANTIC OF ILLNES ACCORDING TO CHALLENGE STATUS

S. No.	Categores	PWD	Guardian	To-tal	PWD	Guardian	Total	CR
		Freq	Freq		% a1	% a2		
1	Presence of disease	19	6	25	18.27	6.52	12.76	2.56*
2	Pain/Ache &Uneasiness	15	6	21	14.42	6.52	10.71	1.72
3	Weakness & inability to work	36	47	83	34.62	51.09	42.35	2.25*
4	Loss of appetite & disturbed leep	2	10	12	1.92	10.87	6.12	2.52*
5	Redundent	31	22	53	29.81	23.91	27.04	0.896
6	Don't Know	1	1	2	0.96	1.09	1.02	
	Total	104	92	196	100	100	100.00	

They are ***'Presence of Disease', 'Pain/Ache & Uneasiness', 'Weakness & Inability to loss of Appetite & Disturb Sleep', 'Redundant' and 'Do Not Know'.***

Table 3.12 revealed that when it was taken as a whole, the meaning of illness revolved around the various health problems. **42.35%** respondent's construe "**Weakness & inability to work" as meaning of illness & they responded like "**आदमी कमजोर हो जाता है चलने फिरने में दिक्कत होती है।". An important finding was that **1.02%** of subjects do not have

awareness of this concept.

With reference to the challenged status a2 predominantly conceived weakness & inability to work as an illness in comparison to a1 **(a_1 =34.62, a_2 =51.09, C.R. = 2.25 < 0.05)**.

Furthermore of PWD_S conceive semantic of illness as **"Presence of diseases".** In comparison to caregivers **(18.27 and 6.25, C.R. = 2.56 < 0.05 level)** with responses like **"जब शरीर मे कोई परे ाानी है तो कोई बीमारी की वजह से होती है।"**

Another difference in their perception was that **10.87%** a2 construe illness as **"Loss of_Appetite and Distributed Sleep"** in comparison to **1.92%** a1 **(C.R. = 2.52< 0.05 level)** with responses like "बीमारी में आदमी को खाना अच्छा नही लगता।". Thus on the whole the typical symptoms of illness seem to be at the basis of their perceived meaning of disease.

B.I.(i)(f) Information base of diseases

The information brought forth various types of ailments, which the subjects frequently experienced. The root asked was : **"आपके यहॉ कौन–कौन सी बीमारियॉ अमूमन होती है।"**After content analysis of the data five major categories emerged that is ***'Infectious Diseases', 'Non Infectious Diseases', 'Pain & Ache', 'Chronic & Long Term Disease', 'Do Not Know'.***

Table - 3.13 : INFORMATION BASE OF DISEASES ACCORDING TO CHALLENGE STATUS

S.No	Categories	a1	a2	Total	CR
		P.W.D %	Guardian %		
1	Infectious Disease	80.19	55.65	67.42	3.56**
2	Non Infectious Disease	8.49	14.78	11.76	1.33
3	Pain & Ache	3.77	20.87	12.67	3.57**
4	Chronic & long-term disease	6.6	4.35	5.43	
5	Do not know	0.94	4.35	2.71	1.85

As is evident from table 3.13, predominantly the respondents of Deva had an information base about **Infectious diseases (67.42%)** Interesting finding had emerged that more of PWDs (a1) reported that they knew more about **"Infectious disease"** in comparison to caregivers (a_2) (**a_1 =80.19% and a_2 =55.65% C.R. =3.56<0.01)** with responds like **"हैजा, मलेरियॉ, चेचक जैसी बीमारियॉ।"** and more of care givers (a_2) seems to be aware of **"Pains & aches"** than PWDs (a1) **(a1 = 3.77 and a2=20.87, C.R. = 3.57<0.01)** with responses like **"सिर दर्द,बुखार आदि होता है।"**

B.I.i.(g) Health Status

Health at a given point of time is to a large extent influenced by the history of health in the past. The question asked was **"अब तक कौन–कौन सी बीमारियॉ आप को हुयी है।"**

Table - 3.14: HEALTH HISTORY ACCORDING TO CHALLENGE STATUS

S. No.	Categories	P.W.D	Guardian	Total	CR
		% a1	% a2		
1	Infectious disease /Seasonal	52.99	40.65	47.08	1.67
2	Bodily pains& Aches	30.6	38.21	34.24	1.08
3	Non Infection disease	9.7	14.63	12.06	1.02
4	Long-term chronic like/ arthritis	3.73	4.07	3.89	
5	None	2.99	2.44	2.72	

As it apparent from table 3.14 data seems to be distributed across all response categories although it was the category of **"Infectious disease / seasonal" (47.08%)"** and **"Bodily pains & Aches" (34.24%)"** which were rather dominant. They responded like **"बुखार,जुखाम,चेचक हुआ है।", "सर्द दर्द, हाथ पैर में दर्द।,"** The picture was rather similar for PWDs & caregivers. Predominantly both feel that primarily **"Infectious disease/ seasonal problems"**, had been the major disease.

B.I.(i) (h) Coping with disease

In the psychological field coping has always meant adjusting to the status. Here coping pertains to emotional reaction and handling states of arousal and stress.

The root asked was **"खुद को ऐसी परे ाानी होने पर आप क्या करते है।"**

Table - 3.15: COPING WITH DISEASE ACCORDING TO CHALLENGE STATUS

S.No	Categories	P.W.D	Guardian	Total	CR
		%	%		
1	Doctor/Hospital	77.59	74.42	76.24	0.63
2	Vaidya/Faith healer	8.62	8.14	8.42	
3	Home based treatment	9.48	8.41	8.91	

4	Chemist's Shop	**0.86**	**6.98**	**3.47**	**2.18***
5	Do Nothing	**3.44**	**2.33**	**2.97**	

The distribution of data in table 3.15 clearly conveys that 76.24% respondents responded **"Doctor/Hospital"** as a coping of disease.*

Table-3.16: Health Perceptions at a glance

HEALTH PERCEPTIONS – AT A GLANCE	
Semantic of Health & Healthy person	• 21% of subjects do not have awareness for the concept of health. Interestingly it was more of PWDs (a1) which has lesser awareness than their caregivers (a2). • Both a1and a2 predominantly conceive '**Absence of illness'** as health. • The caregivers had the traditional conception of health in '**Robust body and strength'** (23.26%) in comparison to 14.43% of a1 **'Healthy habits'** was a positive connotation of health employed more PWDs and caregivers and this was a positive finding.
Essentials of good health	• Nutritious diet is perceived as an essential component for health by both a1 & a2.
Source of health Information	• Doctors & Primary health centre emerge predominantly as the source of information about health.
Semantic of Illness	• The typical symptom of illness seems to be at the basis of their perceived meaning of disease. • 42.35% subjects selected 'Weakness & inability to work' as symptom of illness. • 28.06 % respondents do not have awareness of concept illness
Information base for disease	• More PWDs 80.19% are aware about infectious diseases.
Health history & coping with disease	• Majority of respondents reported that they have seasonal problems… • Villagers mostly prefer to go to doctor/hospital. • Greater percentage of a1 do nothing (3.44%) or take home based treatment (9.48%) in comparison to a2 (2.33% & 8.41% respectively).
RESULTS & ASSUMPTIONS	• The above findings clearly depicts that awareness of villagers regarding health related concepts is fair good. • PWDs have good awareness about health and also

have more knowledge about diseases.

With reference to challenged status, most of the care givers take medicine from chemist's shop comparison to PWDS **(6.98% and 0.86% respectively, C.R. =2.18<.05**). They responded like **"दवा ले आते ह।".**

B.I. (ii) Mental Health Perceptions:

"Mental Health Is The Balanced Development Of The Individual's Personality And Emotional Attitudes which Enable Him To Live Harmoniously With His/Her Fellowmen/Women" (Bansal,2012).

A sound mind in a sound body has been an ancient health prescription. The difference between physical health and psychological health has been drawn on the basis of body and mind respectively. Any damage or change to the person's body- external or internal other than the one required and normal functioning is physical illness but mental health is abstract and not easily visible phenomena. Only one's feelings and perceptions about the external world indicates one's mental health which is primarily obtained from ones experiences through learning at home, school-college, neighbourhood and the culture. If one finds the environment helpful, one is happy and he tries to be a part of it, i.e., he belongs to it and if he finds the environment as obnoxious, hindering and unhelpful, he feels unhappy and withdraws from it. The former leads to mental health and the latter create mental health problem.

This dimension seeks information on 3 sub dimensions.

B.I. (ii) a. Awareness of Mental Health

B.I. (ii) b. Essentials for Mental Health

B.I. (ii) c. Coping

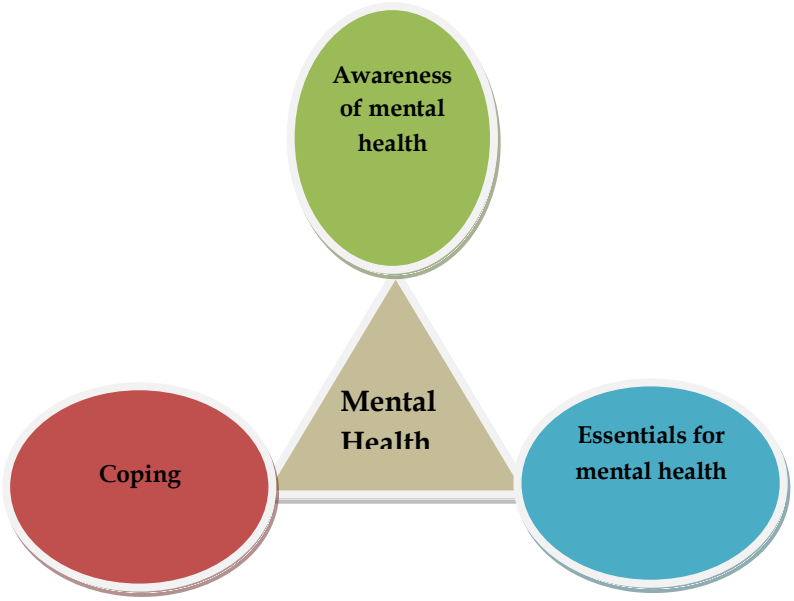


Figure 3.9 Sub Dimensions of Mental Health Perceptions

Results for each sub dimension are being discussed below: **B.I. (ii)**

a. Awareness of Mental Health

This sub dimension seeks information for not only sementic of mentally healthy individual, happiness, sadness and anxiety but also explores awareness of mood states and causes of Mental Disorders as given in fig 3.10.

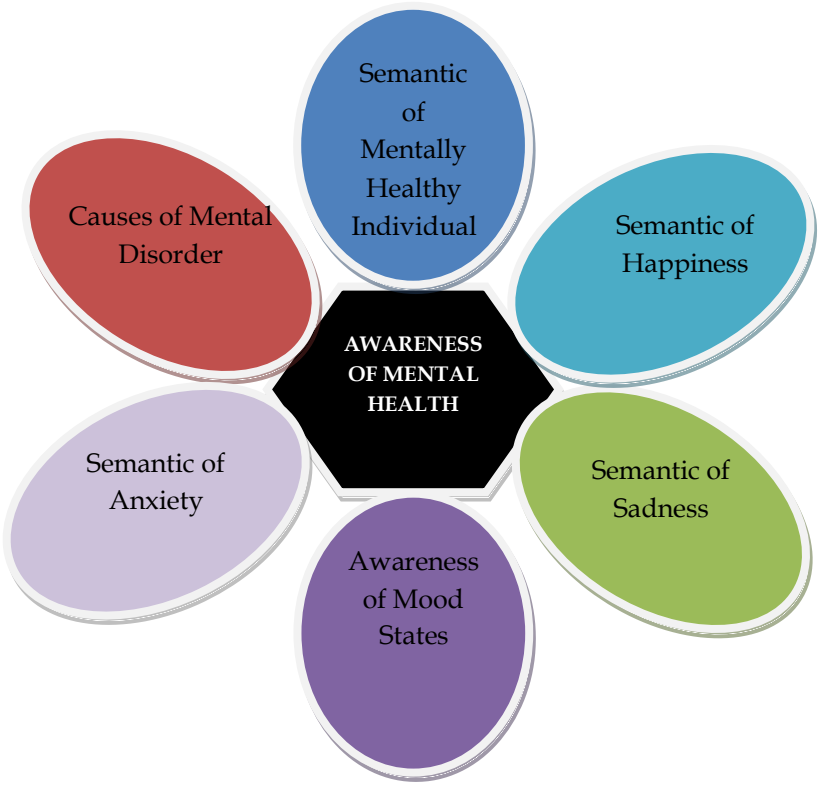


Fig 3.10: SUB DIMENSIONS OF MENTAL HEALTH AWARENESS

* **Semantic of Mentally Healthy Individual:**

The semantic of mental health and that of mentally healthy person had the responses in terms of the latter hence that is being taken up here.

Conceptually Mentally healthy individual is one who attains balance between life activities and efforts to achieve psychological resilience. Moreover, he /she enjoys life to the fullest, does not waste time and energy worrying, seems to have healthy diet, experiences a sense of well-being or satisfaction or happiness in life and has a reasonable degree of emotional, physical and social security**.** *(Heller, 1991; Fierro, 1999; Singh & Mishra, 2000; Holmes, 2006 and medical news today, 2009).*

The question asked was **"**दिमागी तौर पर सेहतमंद कौन होता है? **"** Content analysis of the data evolved five major categories which are as follows *'Intelligent & mentally more functional', 'Positive Thinking & Absence of Worries & Anger', 'Poor Mental Health in Different Circumstances', 'Poverty Etc.', 'Redundant' and 'Do Not Know'.*

Table - 3.17: SEMANTIC OF MENTALLY HEALTHY INDIVIDUAL ACCORDING TO CHALLENGE STATUS

S.No	Categories	P.W.D	Guardian	Total	CR
		% a1	% a2		
1	Intelligent & mentally more functional	71.13	70.93	71.04	
2	Positive thinking& Absence of worries & Anger	5.15	8.14	6.56	
3	Poor Mental Health in Different circumstances,	8.25	11.63	9.84	0.74

	Poverty etc.				
4	Redundant	**0**	**1.16**	**0.55**	
5	Do not Know	**15.46**	**8.14**	**12.02**	**1.54**

Table 3.17 clearly shows the dominance of **'Intelligent & mentally more functional' (71.04%).** The category comprises of responses like – जिसके दिमाग हो, जो अक्लमंद हो, जो अक्ल से अच्छा काम करे, an important finding was that almost **12.57%** of subjects do not have awareness for this concept. Their response were like **"नही मालुम।" Both** a1 & a2 responded in the same way.

* **SEMANTIC OF HAPPINESS**

Happiness is an important sub dimension of mental health, as it directly affects the mental health status of the person. Philosophers and religious thinkers often define happiness in terms of living a good life, or flourishing life rather than simply as an emotion. Happiness is the subjective state of mind construed and felt differently. Thus, it is essential to explore the semantic of happiness. To know the meaning of happiness in the lives of the subjects, the question asked was: "**खुशी से आप क्या समझते है? "**

In line with wide variety of perceptions, this question generated wide variety of data, after content analysis eight major categories have emerged **'Function/Celebration/ Entertainment', 'Happy life events viz Birth of a Child / Healthy Relation/Family', 'Be Tension Free/ Feel Good', 'Completeness Of Any Work Achievement / Favorite Work', 'Material prosperity/Money', 'Being Healthy' and 'Do not Know, 'Redundant'**

Table 3.18 clearly shows that the data seems to be distributed across all response categories however it is the category of **'Work completion or Achievement',** which was rather dominant when the group was taken as a whole **(29.93%)** with response like :-"**कोई चीज हासिल करना कोई बात अपने मर्जी से हो जाऐ, बच्चे पढाई में अच्छा करे।** This was followed by **"Function/ Celebration" (23.36%)** with response like **"घर में कोई शादी ब्याह हो और खुशी हो।"**

Table -3.18 : SEMANTIC OF HAPPINESS ACCORDING TO CHALLENGE STATUS

S.No	Categories	P.W.D. %	Guardian %	Total	CR
1	Family Function/Celebration/ Entertainment	24	22.82	23.36	
2	Happy life event viz Birth of a Child/Healthy relation/Family Environment	7.2	19.46	13.87	2.46*
3	Be tension free/ Feel good	19.2	13.42	16.06	1.05
4	Work completion/ achievement	35.2	25.50	29.93	1.42
5	Material Prosperity/Money	7.2	7.38	7.30	
6	Being Healthy	3.2	6.04	4.74	
7	Do not Know	0	4.69	2.55	0.70
8	Redundant	4	0.67	2.19	

With reference to challenge status **19.46%** a2 construe happiness as "**Happy Life Events viz Birth of a child/ healthy relation"** in Comparison to **7.2% of** a1 **C.R. = 2.46<0.05** level.

* SEMANTIC OF SADNESS

Happiness & Sadness are the two sides of the same coin. The question asked was **"दुःख से आप क्या समझते है" .** Data generated seven major categories of responses *"Experience of sadness", "Synonyms of sadness", "Negative Expressions", Event of sadness (Death, Accident etc.)' "Do not know" "Redundant".*

Table- 3.19: SEMANTIC OF SADNESS ACCORDING TO CHALLENGE STATUS

S.No.	Categories	P.W.D.	Guardian	Total	CR
		% a1	% a2		
1	Experiences of sadness	21.21	32.56	26.5	1.73
2	Synonyms of sadness	3.03	2.33	2.7	
3	Negative Expressions	4.04	3.46	3.8	
4	Event of sadness (Death, Accident etc.)	54.55	61.63	57.8	
5	Feeling of Disability	10.10	0.00	5.4	3.02**
6	Do not Know	1.01	0.00	0.5	
7	Redundant	6.06	0.00	3.2	

SADNESS As above table 3.19 shows the category of "**Event of sadness" (57.8%)** which is predominant comprising of response like 'कौनों चीज का खोई जाना, कौनों जनें का मर जाना,घर मा कौनों का बीमार होई जाना है।'

This is followed by the category of "**Experience of sadness" (26.5%)** with response like:-दुख में सब चीज भूल जाते है।

With reference to challenged status, more of PWDs (a1) "**Feel Sad"** about their disability in comparison to caregivers (a2) **(a1=10.10 & a2=0.00 C.R = 3.02<0.01)**.

Tilak (2002) in her study on slum dwellers reported that death, loss, disease and poverty have been conceived as semantic of unhappiness by 30% of the sample. Similarly, Kumar (2005) found in his study that most of the villagers reported disease and death as the perceived causes of unhappiness.

* **AWARENESS OF MOOD STATE**

Facial expressions are mirror of our emotion. How often people meet and are even aware of the mood, what they feel and carry expressions on their faces. One can manage one's emotions only when one is aware of it. The root asked was. For this sub dimension seven facial expression were provided to the sub section and they had to identify the corresponding emotions in which they stay most of the time **"नीचे दिए गए चेहरों में हर चेहरा मन का एक भाव बताता है?ज्यादातर समय आप इनमें से किस चेहरे में रहते है?उस चेहरे पर निशान लगाएं?"**

Table - No. : 3.20 Mood States of the PWDs and Caregivers

MOOD STATES	PWDs(a1)%	Caregivers(a2)%	Total
 Happy	41.24	23.47	32.35
 Sad	36.08	53.06	44.57
 Anger	4.12	3.06	3.59
 Fear	0	1.02	1.02

Blank		14.43	19.39	16.91
Bored		1.03	0	1.03

From table no. 3.20 it is apparent that accuracy of the expressions "**Sad"** was dominant **36.08%** and **53.06**% subjects report being in sad expression while 32.31% reported most often using a happy face when the group is taken as whole.

With reference to challenge status more of the PWDs **(41.24%)** report **"Happy"** expression on their face in comparison to caregivers **(23.47%) (a1 =41.24 & a2 =23.47%, C.R = 2.55<0.05)** and more of caregivers (a2) report a Sad Expression on their face comparison to PWDs (a_1), **(a_1 = 36.08 & a2 = 53.06, C.R =2.31<0.05)**.

This appears to be a very significant finding and empirically validates the various researches can nothing that raring and caring of the PWDs is difficult, painful and adds to the emotional burden to the care givers. A mentally healthy individual is one who attains a balance between life activities and efforts to achieve psychological resilience. Moreover, he enjoys life to the fullest, does not waste time and energy worrying, seems to have healthy diet, experiences a sense of well being or satisfaction or happiness in life and has a reasonable degree of emotional, physical and social security Heller,1991;Fierro, 1999;Singh and Mishra,2000; Holmes, 2006 and Medical News Today, 2009). On a positive note the findings also convey that more of PWDs seem to have accepted their limitation and reportedly stay in a happy mood. Traces of resilience are evident here the researcher found a validation of their responses through his observations the experiences of the self.

* **SEMANTIC OF ANXIETY**

Anxiety affects our total well-being. It affects how we feel, how we behave and is an important element of our well-being. It is detrimental for filling oomph in one's life or making one dysfunctional. Hence the question tapped was: - **"चिन्ता/ परेशानी से आप क्या समझते है "**

The question pertained to the perceived meaning of anxiety Content analysis of the data brought forth seven major categories. They are *'Consequence', 'Synonyms', 'Symptoms of Anxiety', 'Judgmental Comments', 'Occasion of Anxiety', 'Redundant' and 'Do not Know'.*

Table - 3.21 : SEMANTIC OF ANXIETY ACCORDING TO CHALLENGE STATUS

S. No.	Categories	P.W.D	Guardian	Total	CR
		% a1	% a2		
1	Consequences	7.22	8.14	7.65	
2	Synonyms	7.22	3.49	5.46	
3	Symptoms of Anxiety	12.37	5.81	9.29	0.49
4	Judgmental Comments	26.80	25.58	26.23	
5	Occasion of Anxiety	41.24	46.51	43.72	
6	Redundant	3.09	9.30	6.01	1.76
7	Do not Know	2.06	1.16	1.64	

Almost **43.72%** of respondents construed anxiety in terms of **"Personalized experiences as given in the category Occasions of Anxiety"** based on their experience with responses like **"परेशानी होय जावे पर,घर मा कोइ की तबियत खराब हो जावे पर ।"** On the whole anxiety has been largely construed in terms of own experiences. This is followed by the category of "**अचानक काम आवे पे, काम–धन्धे के बारे मा सोचै पर।".** More a1 addresses anxiety in terms of symptoms in comparison to a2 (12.37% and 5.81%).

Findings were empirically supported by the study of Tilak 2002, Kumari, 2006, Bhatnagar, Srivastava, Singh, Mishra, Sadaf, Srivastava, 2012) where slum dwellers also conceive occasion of anxiety as the perceived meaning of anxiety.

* **CAUSES OF MENTAL DISORDER**

In a disease conscious country like India where people are defining health also as absence of disease, it is any body's imagination as to what will be their understanding of mental health. Hence it becomes imperative to explore the awareness of mental health with reference to the reason/causes of mental health problems.

The question asked was: - **"आपके हिसाब से मन ठीक न रहना बहुत परेशान रहना या, अधिक डरना आदि क्यों होता है?"** The question clearly addresses the information base for the etiology of mental disorders.

After content analysis of data seven major categories have emerged:- Some problem of *'Brain', 'Illiteracy', 'Stress', 'Unhygienic/ Bad Diet', 'Effect Of Other Disease / Accident/ Other Physical Reasons', 'Weakness / Unhealthy Habits Like Drinking' and 'Do not Know'.*

Table - 3.22: CAUSES OF MENTAL DISORDER ACCORDING TO CHALLEGE STATUS

S.No	Categories	P.W.D	Guardian	Total	CR
		% a1	% a2		
1	Some problem of Brain	8.57	9.38	8.96	
2	Illiteracy	1.90	0.00	1.00	
3	Stress	20.00	17.71	18.91	0.39
4	Unhygienic/Bad Diet Seasonal	21.90	16.67	19.40	0.89
5	Effect of other disease / accident/other Physical reasons	23.81	29.17	26.37	0.82
6	Weakness/Unhealthiness habits like Drinking	14.29	14.58	14.43	

7	**Do not Know**	**9.52**	**12.50**	**10.95**	

The distribution of data in table 3.22 clearly indicates the distribution of responses in the etiology of mental disorders for seven categories. Almost **26.37%** of respondents report the cause of mental disorders in terms, of "**Effect of other disease/ accident / other physical reason"** with response like: **"जब देह बहुत पिरात हो और शरीर मा परेशानी होय।"** and **19.40%** unhygienic / "bad diet/seasonal" with response like: **"गन्दगी से, खराब खाना खाने से।" the perception of some a1 and a2 are the same.**

B.I. (ii) b. Essentials for Mental Health

Mental health is the balanced development of the Individuals' personality and emotional attitudes. There is a strong connection between being healthy and being happy. Happiness and personality can also influence the triggering of illness and its prognosis. Authentic happiness of them often mirrors mental health.

The question asked was :- **"अच्छी दिमागी सेहत के लिए क्या जरूरी है"** The question explores '**Essential correlates of Mental health'** After content analysis seven major categories have emerged : *'Nutritious Diet', 'Physical Exercise/ Yoga', 'Study and Entertainment', 'Healthy Family Environment', ' Positive Thinking', 'Do not Know' And 'Redundant'.*

Table - 3.23 : ESSENTIAL FOR MENTAL HEALTH ACCORDING TO CHALLEGE STATUS

S. No	Categoriesz	P.W.D	Guardian	Total	CR
		% a1	% a2		
1	Nutritious Diet	47.79	59.05	53.21	1.51
2	Physical Exercise/Yoga	12.39	9.52	11.01	
3	Study & Entertainment	17.70	18.10	17.89	
4	Healthy family/Environment	8.85	5.71	7.34	
5	Positive Thinking	8.85	4.76	6.88	1.07

6	Do not Know	2.65	2.86	2.75	
7	Redundant	1.77	0.00	0.92	

Table 3.23 indicates that **53.21%** respondents replied, **"Nutritious Diet"** as an essential for mental Health. With responses like नीक खाना,जौन तन्दरूस्ती देवे और शरीरौ का लागे। It was closely followed by category of **"Study & Entertainment" (17.89%). All the respondents feel the same way.**

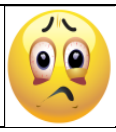
B.I. (ii) c. Coping

Coping means not letting things immobilize you but just getting along. In the psychological field coping has always meant adjusting to the status. Here coping pertains to emotional reaction and handling states of arousal and stress.

Coping has been defined as, the process of managing taxing circumstances, expending effort to solve personal and interpersonal problems, and seeking "to master, minimize, reduce or tolerate stress" or conflict.

Since coping for seven states was explored Table 3.24 gives a composite picture of the dominant response category for each.

Table - 3.24 : METHODS OF COPING WITH EMOTIONS

Emotions	Dominant Response Category	Value in %		Total	CR
		PWD (a1)	Guardian (a2)		
 **Happiness**	Celebrating	37.50	35.05	36.32	
	Laughing enjoying with parents	41.30	19.59	30.85	3.16
 **Sadness**	Silent or sleep	29.90	28.43	29.15	
	Think about solution	28.87	24.51	26.63	0.58
 **Anxiety**	Look for Alternative/ Solution	55.77	40.21	48.26	2.12
	Sharing	23.08	15.46	19.40	1.31

Mental Disorder	Seek treatment/ think Solution	81.82	79.31	80.65	
	Sharing and Relaxing	7.07	3.45	5.38	1.08
 **Problems**	Active Positive (Sharing, Taking action, Facing Problem, Seeing Alternative)	57.73	39.35	50.72	2.44
	Passive Positive (Think, Pray to God)	22.68	48.84	33.49	3.70
 **Tiredness**	Take rest/Relaxed	75.78	72.41	74.18	
	Take some Refreshment	16.41	19.83	18.03	0.6
 **Anger**	Active Negative (beat, Fight, Scolding)	35.05	33.72	34.43	
	Passive Negative (Weep, Do nothing, Stay alone)	21.65	29.07	25.14	1.44

On being Happy casting a glance at the obtained response categories after content analysis brings to fore front their it is a wide variety of coping with happiness. The categories are: "**Celebration/ Entertainment", "Share with People", "Religious Rituals", "Go anywhere/ Buy something", "Laugh/enjoy with Family/ Friend / feel good", "Expand work", "Sleep", "Not Feel/Redundant".**

Myers, 'A' pioneer in happiness commented, "Happiness is less a matter of getting what you want than wanting what you have". How one handles happiness reflects the extent of comfort with happiness in his/her life. The root given was: **खुश होने पर आप क्या करतें हैं?**

Responses show that data seems to be distributed across all response categories. It was a category of **"Celebration/ Entertainment"** which was rather dominant (**36.32%**) with response like "**आस पास के लोगन मा बताशा बाटत है नाचत गात हैं, ढ़ोलक बजावत हैं।**" This is closely followed by **"Laugh/Enjoy with family/Friend" (30.85%)** they respond like: **" घर वालो के साथ बात करते है, हँसते बोलते हैं "**

In terms of challenged status, interesting results have emerged More of a2 reported that they "**laugh, enjoy with family/friend & feel**

good" whenever they were happy in comparison to a1 **(a1=41.30%, a2=19.59% C.R.=3.16<0.01).**

On being Sad: each one of us has our own coping for dealing with negative experiences & life events. The coping is an indicator of Mental Health. Hence the root given was : **" दुखी होने पर आप क्या करतें है?"**Content analysis evolved seven major categories .They are: **'Think About Solution /Sharing and Changing Mood', 'Pray To God', 'Stay Alone /Walking', 'Crying/Feel Sad', 'Anger/Not Able To Understand', 'Silence/Do not Talk to Anybody/Sleep' and 'Nothing/Denial'.**

Response category of **"Silent or Sleep"** has emerged most dominant **(29.15%)** when the group is taken as whole, with responses like: **"किसी से बोलत नाही चुपचाप बैठे रहत हैं। "**

It was also important to mention here that **26.63%** respondent **"Think about solution by sharing with others and changing their mood"** for coping with their Sadness. They respond like **"बइठ कर सोचत हैं और बोलत नाहीं और कुछ काम भी नाही करत है।"**

On being anxious: Anxiety is a state of apprehension that is characterized by feeling of dread worry, nervousness, or fear however; it is the experience of anxiety and belief about one's ability to cope with the same, which decides one's mental health. The response categories which emerged were eight: '**Alternative/ Solution', 'Stay Alone & Peacefully/ Go On Work', 'Share With Family/ Other Person', 'Remember God', 'Experience', 'Take Medicine', 'Treatment', 'Do Not Know/ Nothing' And 'Redundant'.**

A perusal of the table indicates that category of **"Looking for alternative/ solution"** is rather dominant (**48.26%)** with response like **"चिंता का दूर करै का तरीका ढूढ़त है जैसन कौनउ काम नहीं हुआ तो सोचत है कि उ**

काम होई जाये।" This is closely followed by the category of **"Sharing" (19.40%)** with response like: **"उमर में बड़े लोगन से सलाह लेत है। "**

With reference to the challenged status, more of a2 are reporting **"Being with experience of anxiety"** as a coping strategy with anxiety in comparison to a1 **(a1=3.85% and a2= 14.43%, CR= 2.51<0.05)** they respond like: "उलझने होती है कुछ काम करने की इच्छा नहीं होती है दुखी परेशान रहतें है।" Further **55.77%** PWDs (a1) respond that they t "**look for alternative/ solution"** when they feel anxious in comparison to caregivers (a2) **(a1=55.77 & a2=40.21, CR=2.12<0.05) (Srivastava, 2009)**

Coping with Mental Illness: is unfortunately still a stigma due to lack of awareness. Often the patients are mishandled due to lack of understanding. The root given was: **" इनके होने पर आप क्या करते है?"** Question explores the coping used in dealing with mental diseases. Content analysis generated seven major categories. They are "**go to doctor/ treatment/ think solution", "hygiene", "Share with family or relatives/ relaxed", "Remember to god/ worship", "Negative attitude (anxiety, anger)", "Nothing", "Do not know".**

Results clearly indicate two major coping patterns. It is the category of **"Seek treatment/ think solution"** which is rather dominant (**80.65%)** eg- **"डॉक्टर को दिखात है।"**

An Interesting finding has emerged that more of a1 reported, **"They do not know, How to cope with mental disorder"** in Comparison to a2 **(a1 = 0.00, a2= 5.75%, CR= 2.39<0.**

Coping with Problems: "Every problem be it with relationship Finances, health, or self image has a solution in the sacred self" Dyer. People using problem-focused strategies try to deal with the cause

of their problem. They do this by finding out information on the problem and learning new skills to manage the problem. Problems are only a reminder to one's relief that one is still alive and throbbing with life. However, what is a simple trivial day today life problems for one may become a matter of life and death for another. It depends on how one perceives it. The root given was: **"जब परे ाानी आती है तो आप क्या करते है?"**

The data was voluminous and after Content Analysis of the data five major categories emerged: **Active Positive** (**Sharing, take action, Facing, problem, Alternative), Passive Positive (think solution, Pray to God), Active Negative (Abuse, Smoking, and Restlessness), Passive Negative (Headache, Hopelessness), Do not know**.

It is clear that category of **"Active Positive"** which is rather dominant **(50.72%)** This comprises of responses focused on sharing, taking action, and facing problem. They respond like: **" घरवाले जानकार लोगन से सलाह लेत है। "** This is closely followed by the category of **"Passive Positive" (33.49%)** response like: **" अकेले बैठ कर सोचते है। "**

On being Tired: Tiredness shows energy level of the person and it depends on the work pressure. The root given was: **"काम के बीच थकान को कम करने के लिए क्या करतें है?"** Content analysis brought forth four major categories viz: "**Take rest/Relaxed", "Take some Refreshment", "Entertainment (T.V, Gossip, and Music)", and "Redundant".**

Data seemed to be distributed across all four response categories although it was the category of **"Take rest/ Relaxed"** which was rather dominant **(74.18%)** with responses like: **आराम करत हैं।"** Rest of the data was sparsely distributed among other category. Both PWD_s and caregivers think in a same way.

On being Angry: Anger is a prime emotion. It reflects negativity. This information gives idea about how the respondents react to anger. The root given was: **"अमूमन गुस्सा आने पर क्या करतें है?".** After content analysis of the data four major categories have emerged: **Active Positive (Walk, laugh), Passive Positive (Think, sleep, Stay alone Relaxed, Controls), Active Negative (beat, Fight, Scolding), Passive Negative (Weeping, Nothing, Stay alone, do not Know).**

Responses present a clear picture that largely villagers of Deva block are dealing with anger in an **"Active Negative"** mode. They reported violent behaviour with responses like: **"मार देत है और घर वालों पर चिल्लात हैं।"** The responses showed need of some intervention here. Both PWDs and caregiver feel the same way.

Major observations of the Perception about Mental health, are as follows:-

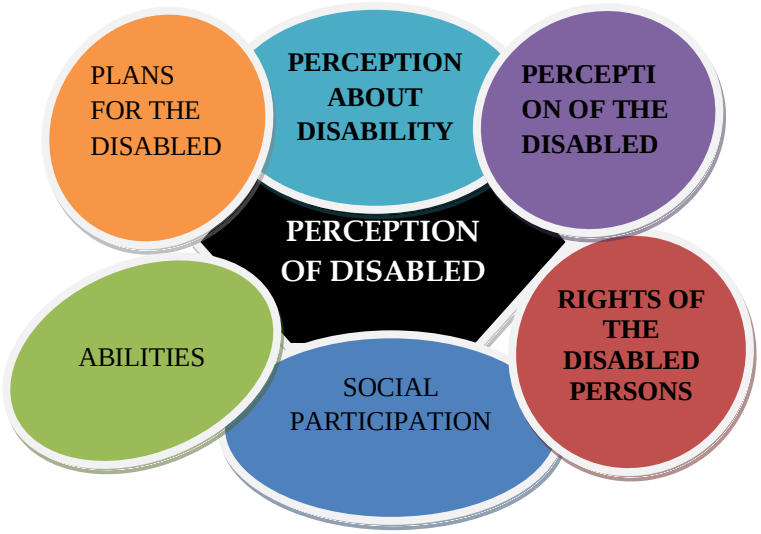
- "Mental Health" has been largely defined as the mentally healthy person, a1 and a2 both respond in a same way for mentally healthy individual as one with a lot of intelligence.
- More of PWDs construe **happiness** in terms of completeness of any work and achievement. **They cope with unhappiness or sadness** largely by being silent or sleeping. On the other hand they look for an alternative to deal with anxiety. The personalized events seem to dominate the responses of anxiety. What bothers is the finding of aggressive outburst which could indicate some emotional expressions and somewhat poor impulse control.
- Another point of concern is that predominantly 53.06% of guardians have a constant expression of sadness while 41.24% of PWDs report happy expression. More PWDs appear to be happy.

❖ Nutrition's diet has been construed as most essential for mental health paradoxically they do not eat nutrition food.

B.I. (iii) Perception of disability:

Awareness implies the building up of knowledge and capability for seasoning based on logical facts rather than affective factors. The capacity to reason depends upon the extent and accuracy of the information flow from different sources associated with certain amount of authenticity to improve the credibility of information and its acceptance.

This dimension generated information on six sub dimensions:-



Figure–3.11: Sub Dimensions of Perception of Disabled

Results of each sub dimension are being taken up one by one. Responses on these six dimensions were obtained using sentence completion blank pertaining to each sub dimension this was done to obtain spontaneous and genuine response of both PWDs and caregiver since disability is itself stigmatized concept to minimizing social disability effect is the semi projective technology of sentence compilation blank was used.

B.I. (iii) a. Perception about Disability

Despite development medical information technology people at large still carry a lot of stigma for disability. They take them either in a sympathetic way or in a negative way. The root given here was – **"इस प्रकार की दिक्कत/कमी के बारे में आप क्या महसूस करते है?"** content analysis of the data brought four major categories : "**Positive", "Negative" , "Indifference" and "Do not know"**.

Figure-3.12: Perceptions about Disability

	PWD	Guardian	Total
 Positive	24.79%	19.77%	22.40

	PWD	Guardian	Total
 Indifference	13.40%	3.49%	8.74

	PWD	Guardian	Total
 Do Not Know	3.09%	5.81%	4.37

	PWD	Guardian	Total
 Negative	58.76%	70.93%	64.48

It is clear depicted that a total of **64.48%** respondent's reported **"Negative"** feelings about disabilities with responses like. **"ये लोग/हम कुछ**

नही कर पायेगे।" According to challenge status more of PWDS seems to be indifferent or neutral for disability in comparison to caregiver **(a1=13.40 & a2=3.49, C.R=2.35<0.05)** with response like **"कुछ महसुस नही करते है।"**

The findings collaborate or support the results of Mental Health (in the section of awareness of mood state) there is dominance of negative mood over the other three responses as felt perception about disability. The fig. 3.12 clearly demonstrate that more guardian 70.93% have different perception of disability in comparison to PWD 58.76%.

The one whelming negative perception 64.48% of respondents shows the 22.40 positive perspectives. 8.74% indifference and 4.37 do not know.

Another interesting finding worth noting that denial marked as indifference for not feeling anything about disability issue the avoidance in giving responses again shows their negativity about the issue.

The researcher felt it in comparative to explore a detailed picture for the challenged person as captured in the perception of both PWDs and guardian for these four major issues have been taken below:

1. **Perception of the disabled**
2. **Other people perception**
3. **Economic & financial dependence**

The results pertaining are given as follows:-

B.I. (iii) b. Perception of the Disabled

Disabled Persons are…….	Perception of villages for PWDs……

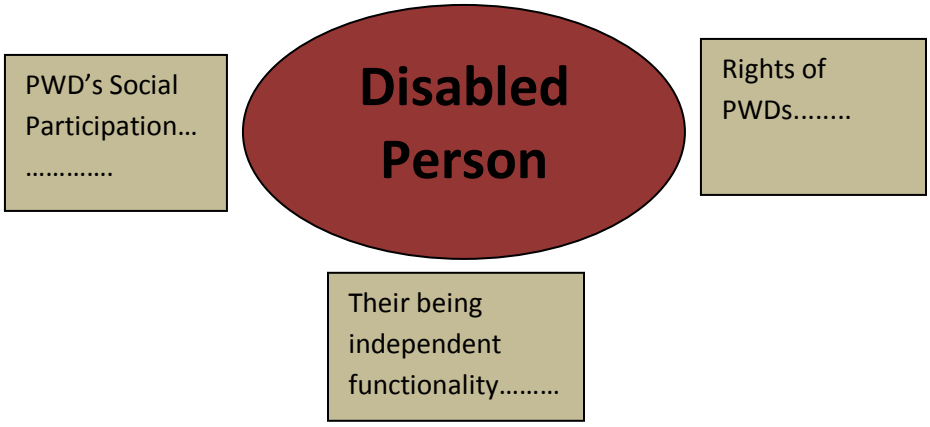


Figure - 3.13 : Perception of the PWDs.

1. PERCEPTION OF THE DISABLED

The spontaneous first reaction to the incomplete sentence of reflects ऐसे लोग .... their felt perception for the disabled person. After content analysis of the data three major categories have emerged: "**Positive /Factual", "Negative" And "Don't know".**

Figure - 3.14 : Perceptions of the Disabled

PWD	Guardian	Total	
57.00%	53.49%	55.38%	 Positive

PWD	Guardian	Total	
37.00%	38.77%	37.63%	 Negative

PWD	Guardian	Total	
6.00%	8.14%	6.99%	 Do not know

It was noted that a total of **55.38%** gave a **"Positive" & compassionate** responses like: **"इनके लिये दुकान खुला दी जाय, इनको तकलीफ न हो, इनकी नौकरी का इन्तेजाम हो।".**

On the other hand **37.63%** respondent gave **"Negative view"**. With response like **" इनके जौन करम होइहैं उहै तो झेलिहैं।". 6.99 % respondent expressed that they Do not know what perception they have.**

* **PERCEPTION OF THE VILLAGRES FOR PWDs**

The researcher explored the villager's perception in general for the disabled persons. The root given was: **"ऐसे लोगो के प्रति आपके गॉव के लोगो का नजरिया.....** " After content analysis of data four major categories have emerged **"positive", "Negative", "ambivalent", "Do not know".**

Figure - 3.15 : Perception of the villagers about PWDs.

PWD	***Guardian***	***Total***	
47.42%	50.00%	55.38%	**Positive**
44.33%	39.53%	42.08%	 **Negative**
7.22%	8.14%	7.65%	 **Ambivalent**
1.03%	2.33%	1.64%	 **Do not know**

Other people's perspective the figure also shows that though statistically significant more PWDs perceive the villager's attitude negative. 39.53% guardians report negative perspective of the villagers than the PWDs though it is only the marginal difference.

Distribution of data in figure 3.15 clearly shows that almost **55.38%** respondent reported a positive perception of the villagers viz **"Positively"** like. **"गॉव वालो का नजरियॉ अच्छा है सब चाहे कि इनको सब सुविधा मिल जाये।"** It is followed by **"Negative"** responses **42.08 %** like. **"अच्छा नही है साथ नहीं देते है।**

✓ **ECONOMIC /FINANCIAL INDEPENDENCE**

Economic Independence is an area which adds to peoples' well being and self esteem. The root given was **"इनका अपने पैरों पर खड़ा होना।"** Content Analysis of the data brought forth three major categories; **"Essential", "Small business /job /farm activities/ education", "Do not know".**

Table - 3.25 : Economic /FINANCIAL INDEPENDENCE- Standing on their feet

	PWDs	Guardian	Total	CR
Essential	41.24	48.84	44.81	1.03
Small Business/ job/Farm Activities/Education	55.67	50.00	53.01	0.77
Do not know	3.09	1.16	2.19	

The results very clearly shows on the hold both the PWDs as well as the guardians feels that being the PWDs it is very essential to be independent for the disability on a positive note 50% has given a very

concrete optional and almost 45% got the economic independence for them.

The results also show two more interesting trends. The responses are largely on normative perception of should the other finding is that more of PWDs in comparison to their caregiver have given concrete options of small job 53.01 options though the difference is statistically indifferent.

Table 3.25 shows that it is a category of **"Small business/ job/farm activities / education"** which is rather dominant (**53.01%)** with response like **"इनके लिये कमाने के लिये काम धन्धा करना चाहिये।"**. This perception is judgmental as well as solution focused. It is closely follows by the category of **"Essential" 44.81%** with responses like. **"जरूरी है,कोई काम करना चाहिये।".**

B.I. (iii) Rights of the Disabled

To provide access to the legal system and improve facilities for person with all type of disabilities, the disability rights Initiative (DRI) provides legal aid and takes up high impact public interest litigation. The root given was: - **"इन कमियों के साथ रहने वाले ; (विकलॉग) लोगो के अधिकार ..."**.

After content analysis of the data five major categories have emerged: Government, Facilities/Reservation, Education, Job/ Fullfill Primary Need, Equality, Do Not Know.

S. No.	Categories	P.W.D	Guardian	Total	CR
		%	%		
1	Government Facilities/Reservation	55.56	51.26	53.54	
2	Education	15.56	10.08	12.99	1.10
3	Fulfill Primary Need	10.37	18.49	14.17	1.57
4	Equality	14.07	18.49	16.14	
5	Do not know	4.44	1.68	3.15	

Table - 3.26: RIGHTS OF DISABLED PERSON ACCORDING TO CHALLENGE STATUS

The table 3.26 indicates that it is a category of **"Government Facilities/ Reservation"** which is rather dominant **53.54%** with reference like. **"विकलांगों को भी आरक्षण का तहत नौकरी, रहने की व्यवस्था और पेंशन मिले।"** Rest of the data is sparsely distributed among other category. Both PWD_s and caregivers think in a same way about **"Rights of Disabled Persons"**.

The results are an eye opener for the policy makers as well as people working in the areas of disability. Despite the lot of voice about the right to education, equality and other things primarily it is a reservation which has found an entry into their awareness zone as most of them are talking about the rights in term of job reservation and government facility. There is a marginalised percentage for Right to Education (RTE) Act with only 12.99%.

This is an important finding for people working in education sector particularly in integrating the disabled into mainstreaming. It is a matter of serious concern and need to be addressed both in policy and ground

reality level. Though it is a small percentage yet 3.15% respondents are not even aware about the right of PWDs.

B.I. (iii) d. Social Participation

PWDs are also a part of our society. They can also take responsibility and make more efforts. If we support them and give them a chance, they can do much better in their field. The root asked was:

Content analysis evolved five major categories .They are: "**In social activities/Vocational", "Essential/ According to their ability", "Vote", "Like normal person/Equal" and "Do not Know"**.

Table - 3.27: RIGHTS OF DISABLED PERSON ACCORDING TO CHALLENGE STATUS

S. No.	Categories	P.W.D %	Guardian %	Total	CR
1	In Social Activities/Vocational	63.00	62.50	62.77	
2	Essential/According to their Ability	17.00	12.50	14.89	0.85
3	Vote	3.00	2.27	2.66	
4	Like Normal Person/Equal	16.00	15.91	15.96	
5	Do not Know	1.00	6.82	3.72	

As is clear from table 3.27 it is the category of **"In Social Activities/Vocation**

सकत है वउ भी काम कराइक चाही ।".

The results are in terms of reality and need more fine tuning in terms of other areas of social participations. On a healthy note only a small percentage of respondents conceive the participation of disabled as non challenged people. This sensitization and awareness need more emphasis, the mindset at the people at large at the rural set up needs to be changed and for this the researcher feels the **community empowerment model** is the need of the hour.

Both PWDs and caregivers think in the same way. Mostly respondents think that PWDs should have more participation in social activities and vocational work. **15.96%** respondents respond, **"We should take PWDs like normal person"**. Rest of the data is sparsely distributed among other categories.

B.I. The Resource potential of the PWDs:

The growth model of community development takes into account the deficits build upon by the capacities therefore, the perception of the PWDs of the guardians were explored with reference to exploring perceptions regarding the PWDs, capacities, limitations, safety parameters and provisions.

The resource potential addresses both the innate potential in terms of capacities, limitations, challenges and safety measures in terms of activities and finally the resource to be given by government and other sectors. On the other hand the resource reservations in terms of capacity explore the kind of job they can do.

CAPACITIES - Person's opinion shows their perception about environment. To know how the people of Deva Block think about the working ability of PWDs, they were asked the question:

"अब बताईये कि कमियों, दिक्कतों विकलांगता वालों के लिये आप के अनुसार (अ) क्या –क्या काम ये कर सकते हैं।" The data was voluminous after Content Analysis of the data five major categories emerged:

(1) "Small Business /Govt. Service", (2) "Teachers/ Computers", (3) "Farm Activities", (4) "Tailoring/ Embroidery Work", (5) "According to their ability", (6) "Nothing".

Sl.No	Categories	P.W.D	Guardian	Total	CR

		%	%		
1	Small Business /Govt. Service	29.79	47.41	38.41	2.44*
2	Teachers/Computers	13.48	6.67	10.14	1.51
3	Farm Activities	12.77	8.89	10.87	
4	Tailoring/ Embroidery Work	28.37	28.89	28.62	
5	According to their ability	15.6	7.41	11.59	
6	Nothing	0	0.74	0.36	

The data seems to be distributed across all categories although it is the category of "**Small Business /Govt. Service**" which has obtained maximum number of responses **(38.41%)** like **"**दुकान खोल कर बैठ सकते है। पढने लिखने पर नौकरी कर सकते है। **"**It is closely followed by category of "**Tailoring/ Embroidery Work**"**(28.62%).**

With reference to challenge status, the result appear rather interesting more of caregivers (a2) think **"Small Business/ Govt. Service"** more suitable for PWDs **(a1=29.79 & a2=47.41, CR=2.44 < 0.05).**

Limitations - The root asked was **"**क्या–क्या काम ये नही कर सकते हैं?**"**A wide variety of data was generated which after content analysis brought forth five major categories.

They are "**Heavy Work/Hard Work/Can't Stand", "Farm activities", "Field Work/Abuse", "Redundant", "Do not Know/Nothing".**

		%	%		
	Heavy Work/Hard Work/Can't Stand	30.93	49.19	41.18	2.51*
	Farm activities	45.36	37.1	40.72	1.13
	Field Work/abuse	23.71	10.48	16.29	2.35*
	Redundant	0	2.42	1.36	

	Do not Know/Nothing	**0**	**0.81**	**0.45**	

The data mentioned in the below given table 3.28 indicates the category of "**Heavy Work/Hard Work/Can't Stand**" which is rather dominant **41.18%** when the group is taken as whole the category comprises of responses like: **"ज्यादा मेहनत का काम नही कर पायेगे बोझा नही उठा पायेगे।"**Closely followed by "**Farm activities**" **(40.72%)** they respond like **"खेती नही कर सकते है।"**

According to challenge status, more caregivers (a2) respond "**Heavy Work/Hard Work/Can't Stand"** in comparison to PWDs (a1) **(a1=30.93 & a2=49.19, CR=2.51 < 0.05)**. Another finding pertaining to more PWDs conceive "**Field Work/abuse**" in comparison to their counterparts **(a1=23.71 & a2=10.48, CR=2.35 < 0.05)** with response like. **"ज्यादा चलने फिरने का काम नही कर सकते है। शराब नही पीना चाहिये।"**

RESTRICTIONS - The root asked was: **"क्या–क्या काम इन्हें नही करना चाहिये।"** The data was voluminous after Content Analysis of the data five major categories emerged: **"Dangerous work", "Gambling/Abuse/Fight", "Heavy &Hard Work", "Driving/ Swimming/ Climbing/Electronic", "Field Work", "Which cannot do", "Redundant/Denial", "Do not Know".**

S.No	Categories	P.W.D	Guardian	Total	CR
		%	%		
1	Dangerous work	16.36	11.11	14.00	1.02
2	Gambling/Abuse/Fight	22.73	6.67	15.50	3.02**
3	Heavy &Hard Work	22.73	38.89	30.00	2.37*
4	Driving/Swimming/Cli	20.00	21.11	20.50	

	mbing/Electronic				
5	**Field Work**	**6.36**	**5.56**	**6.00**	
6	**Which cannot do**	**7.27**	**10.00**	**8.50**	
7	**Redundant/Denial**	**0.91**	**2.22**	**1.50**	
8	**Do not Know**	**3.64**	**4.44**	**4.00**	

As is clear from data it is the category of "**Heavy & Hard Work**" which is rather dominant **30.00%** when the group is taken as whole the category comprises of responses like: **"बोझा नही उठाना चाहिये।"**

Closely followed by "**Driving/Swimming/Climbing/ Electronic**" **(20.00%)** they respond like **"पेड पर नही चढना चाहिये और नदी तालाब में नही तैरना चाहिये।"**

With reference to challenged status, more PWDs told that they should not do "**Gambling/Abuse/Fight"** in comparison to caregivers. **(a1=22.73 & a2=6.67, CR=3.02 < 0.01)**with response like. **"खाली होने पर जुआ नही खेलना चाहिये हिसाब से खर्चा करना चाहिये। किसी से झगडा नही करना चाहिये।"**

Interesting finding have emerged that more of caregiver (a2) reported, "**Heavy &Hard Work**" Comparison to PWDs (a1) **(a1=22.73 & a2=38.89, CR=2.37 < 0.05)**.

Table - 3.28: ABILITIES OF PWDS AND CAREGIVERS

ABILITIES	*a1*	*a2*	*Total*
Can Do → Permissions			
• **Small Business /Govt. Service**	**29.79**	**47.41**	**38.41**
• **Tailoring/ Embroidery Work**	**28.37**	**28.89**	**28.62**
Cannot do → Challenges			
• **Heavy &Hard Work**	**30.93**	**49.19**	**41.18**
• **Farm Activities**	**45.36**	**37.1**	**40.72**
Should not do → Normative			
• **Heavy Work/Hard Work/Can't Stand**	**22.73**	**38.89**	**30.00**
• **Driving/Swimming/Climbing**	**20.00**	**21.11**	**20.50**

B.I. (iii) f. Plans for the Disabled

The root asked was: **"इनके लिए क्या–क्या होना चाहिए और क्या–क्या नहीं होना चाहिए?** Content analysis of the data evolved six major categories. They are: **"Government Facilities/ Reservation", "Education", "Fulfillment of Primary needs", "Sympathy &Love", "Equality in Society", "Do not know".**

Table - 3.29 : PLANS FOR DISABLED PERSON ACCORDING TO CHALLENGE STATUS

S.No	Categories	P.W.D	Guardian	Total	CR
		%	%		
1	Government. Facilities/Reservation	55	72	62.08	2.37*
2	Education	16.43	1	10	3.6**
3	Fulfillment of Primary needs	17.14	19	17.92	
4	Sympathy &Love	5.71	3	4.58	
5	Equality in Society	5	0	2.92	2.1*
6	Do not Know	0.71	5	2.5	1.79

Table (3.29) indicates that the data seems to be distributed across all categories although it is the category of "**Government facilities/reservation**" which has obtained maximum number of responses **(62.08%)** like **" रहन के खातिर आपन घर होइक चाही, आवे जावे के लिये सुविधा, पेंशन का इन्तेजाम और पढ़ाई का इन्तेजाम होन चाही।"** On other hand **17.92%** respondents respond "**Fulfill their primary needs"**with response like **खाना,कपडा और रहने की सुविधा होनी चाही।".**

With reference to challenged status, the results appear rather interesting more of caregivers (a2) think "**Government facilities/reservation**" is more essential plan for PWDs **(a1=55 & a2=72, CR=2.37 < 0.05)** and more of PWDs reported, "**Education**" Comparison to caregivers (a1) **(a1=16.43 & a2=1, CR=3.6 < 0.01) "शिक्षा की सुविधा मिलनी चाहिये।"**.

Interesting finding have emerged that more of PWDs (a1) reported, **"Equality in society"** as a plan for own self **(a1=5.00 & a2=0, CR=2.1<0.05).**

Major observations of Perception of the disabled, are as follows:

- A1 and A2 both think in the same way towards rights of disabled person. They predominantly take Government facilities and reservation as a right of disabled person.
- They perceive independence as earning by any source viz. small business, job, farm activities etc.
- A1 and A2 strongly recommend participation of disabled persons in social activities.
- Government facilities and reservations emerge as a most essential plan for PWDs.
- A1 and A2 both have negative thoughts about disability. However, PWDs feel more indifferent about their disability.
- Another very interesting finding is that A1 and A2 both feel negative about disability but they perceive and think in a positive manner about disabled person.

B.I. (iv) Substance Dependence

To know the status of substance user in Deva Block, the question asked was: **"क्या आप तम्बाकू ,बीड़ी, शराब या सिगरेट लेते हैं या घर में कोई और लेता है?** After content analysis of the data four major categories have emerged: "**Depend", "Some Time", "Nobody in House".**

Table - 3.30 : SUBSTANCE ACCORDING TO CHALLENGE STATUS

S.No	Categories	P.W.D %	Guardian %	Total	CR
1	Depend	80.41	72.09	76.50	1.32
2	Some Time	19.59	3.49	12.02	3.34**
3	Nobody in House	0.00	24.42	11.48	5.16**

What emerges from as the paired finding is that 76.50% (a1 80.41% and a2 72

Phase B.

Section II- MENTAL HEALTH STATUS

At present anxiety, depression & stress are the most frequently used words in the common men's life. Life echoes with daily hassles, pressure to perform deadlines, frustrations and demands. They have become part of the existence and as such are often left unattended or misinterpreted due to lack of awareness. People with mental disorders experience significant disability (i.e. limitations of functioning at the physical, personal and societal levels) and poor Quality of Life and their families and communities are greatly affected. **WHO, 1999**

The present section deals with the respondents' physical, cognitive, emotional and behavioural experiences at times of adverse circumstances of their life leading to anxiety, depression & stress as measured through ADSS items.

At the outset of researcher would share his observations during administration of ADSS that the respondents were not just giving Yes/No for the items, but were narrating evidences from their lives and had something or other to say in support of their responses. After obtaining the scores of all the respondents on ADSS, the mean scores and SDs were computed. Table 3.23 brings to fore a comprehensive picture of the obtained mean scores and Standard Deviation (SD) on all the three dimensions of anxiety, depression and stress.

Table - 3.31 : Sub Dimensions of Mental Health Status

S.No	Dimensions	Score Range	Means		SDs'		Mean of Total
			A1 PWDs	A2 Guardian	A1 PWDs	A2 Guardian	

1.	Anxiety	0-19	8.1	8.72	4.16	4.93	8.41
2.	Depression	0-15	6.36	6.39	4.28	4.73	6.38
3.	Stress	0-14	7.83	7.93	3.45	3.08	7.88

The major observations of table 3.31 are being reported here briefly before taking up the results of each dimension:

- All the three dimensions viz. anxiety, depression & stress show a higher range of means when compared to their maximum scores.
- There seems to be found a very minor difference existing between A1 and A2 for their three dimensions wherein guardians are slight ahead of their counterparts in terms of mean scores.

The results of each dimension are being discussed here-:

B.II. (i) Anxiety

Anxiety is a general feeling of apprehension about some possible untoward happening. It is a condition that often occurs without an identifiable stimulus.

Anxiety (also called worry) is a psychological and physiological state characterized by somatic, emotional, cognitive, and behavioral components. **(Walker, E.F. & Rosenhan, D.L. Abnormal psychology, (4thed.) New York)** It is the displeasing feeling of fear and concern.[3] **(Davison, Gerald C. (2008)**. The root meaning of the word anxiety is 'unease or trouble'; in either presence or absence of psychological stress, anxiety can create feelings of fear, worry, uneasiness, and dread **(Bouras, n. and Holt, G. (2007).)**

Kaplan, H. and Sadock, B. in the *Concise Textbook of Clinical Psychiatry* (1996) state that anxiety "is characterized by a diffuse, unpleasant, vague sense of apprehension, often accompanied by

autonomic symptoms, such as headache, perspiration, palpitations, tightness in the chest, and mild stomach discomfort". They comment that a person who is anxious often feels restless and unable to be still for long.

From these definitions, we can conclude that anxiety is an unpleasant feeling of apprehensiveness. It often includes physical symptoms. If anxiety becomes debilitating and chronic, it may be diagnosable as an anxiety disorder.

The items included in the anxiety scale were not just limited to physical symptoms like heart palpitation, muscle weakness and tension, fatigue, nausea, chest pain, shortness of breath, stomach or headaches but also comprised of emotional stress viz. feelings of apprehension or dread, difficulty in concentrating, feeling tense or jumpy, irritability and restlessness etc.

A perusal of tables 3.24 clearly shows that taken as whole the sample's mean score for anxiety is 8.41. when compared to the total score for anxiety (that is 19) it shows that subjects experience fairly high amount of anxiety in their lives, with guardian ahead of PWDs in their experienced anxiety (means 8.1 & 8.72 for A1 and A2 respectively).

Kuruvilla & Jacob cited in their study that minor or non-psychotic psychiatric morbidity that is largely constituted by symptoms of anxiety and depression are frequently encountered in the general population. These are among the most important causes of morbidity in primary care settings and produce considerable disability.

At this point it would be relevant to cast a glance to the items that have contributed to the high scores in terms of endorsement. Taking up the cutting point of 55% for endorsement, table 3.26 clearly reflects that three out of nineteen items have endorsement percentage greater than

55% for both PWDs and guardians. Out of these two items (Item number 1and 25) are loaded on physical symptoms. A cursory glance at the verbatim response would illustrate the felt anxiety at the physical level.

Endorsement on Anxiety scale clearly shows that the overall endorsement is highest for item number 1 that is 95.19, which states that "*I am aware of the dryness of my mouth*". The subjects replied as "पानी पियत पियत थक जात मुँह वेसन के वैसन ही सुखात है।''

The two next overall percentages for endorsement are item number 20 and 25. In which one states about anxiety at physical level as '**I feel weak and get tired easily'** the responses were: थोड़ा सा भी चलत है तौ हाथ पैर कांपै लागत है। बिल्कुल भी नहीं चलत जात, पेट गुड़गड़ात है हमार, बिस्तर से एकदम से उठ के बइठौ तौ आँखन के सामने अंधेरा छा जात है, अब नाहीं चला जावत, थकान लागै लागत है जईसै चक्कर आई जाई।

The other response having psychological level anxiety is number 20 viz I am worried about those things in which I might panic and make a fool of myself. The responses were given like: 'कौनो बात नहीं फिर भी डर लागत है' अइसन जोर का धरकत है कि लागे कि अभी बाहर आ जाई। 'आवाज तेज रहत है कभी कभी घबराहत जल्द ही लागे लागत छोटी छोटी बातन पर''।

Table-3.32 : ENDORSEMENT PERCENTAGE FOR ANXIETY SCALE

Item no.	Details of the item	Endorsement Percentage		
		A1 (PWDs)	A2 (Guardian)	Total
1	I am aware of the dryness of my mouth	96.91	93.48	95.19
2	I feel difficulty while breathing (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion.)	26.80	29.35	28.08
7	I often have a feeling of numbness in my hands and legs(e.g. legs going to give away)	44.33	42.39	43.36
11	I often have the feeling of faintness	22.68	32.61	27.64

14	I perspire heavily even in the absence of physical exertion and high temperature(e.g. sweaty hands)	40.21	36.96	38.58
15	I get scared without any good reason	32.99	25.00	29.00
18	I have difficulty in swallowing	15.46	23.91	19.69
20	I am worried about those things in which I might panic and make a fool of myself.	74.23	75.00	74.61
21	I feel more nervous and anxious than usual.	59.79	54.35	57.07
24	I am bothered about headaches, neck and back pains.	50.52	55.44	52.98
25	I feel weak and get tired easily.	72.16	70.65	71.41
28	I can feel my heart beating fast.	42.27	50.00	46.13
32	I get feelings of numbness and tingling in my fingers, toes.	38.14	46.74	42.44
34	I am bothered by stomacheache and indigestion	35.05	41.30	38.18
35	I have empty my bladder often.	32.99	34.78	33.89
39	I have nightmares.	34.02	31.52	32.77
41	I have heavy pressure in the chest.	35.05	35.89	35.46
45	Sometimes my vision is blurred.	34.02	48.91	41.47
47	Often I have feeling of nausea.	22.68	28.26	25.47

Both PWDs and guardians are showing psychological traits with having endorsement value of 74.23 and 75.00 respectively for item number 20 which states that "***I am worried about those things in which I might panic and make a fool of myself***". And the subject reported "घबराहट जल्द ही लाग लागत छोटी छाटी बातन पर"।

The results clearly reflect that not only the respondents are more sensitive and aware of their bodily symptoms they experience in their daily lives but their disclosure for the same is also very high.

B.II. (ii) Depression

Depression refers to a range of mental conditions characterized by persistent low mood, absence of positive affect (loss of interest and enjoyment in ordinary things and experiences), and a range of associated

emotional, cognitive, physical, and behavioral symptoms. Symptoms occur on a continuum of severity, and day to day functioning is often impaired. - **National Collaborating Centre for Mental Health, 2009**

While mental disorder includes a range of illnesses (such as anxiety, schizophrenia and autism); depression is the most common and worldwide pervasive disorder **(Worley, 2006).** It seriously reduces the quality of life for individual and their families, is a risk factor for suicide and often worsens the outcome of other physical health problems.

When compared to the total score of 15 the mean score for depression is 6.58 (table 3.25) showing that subjects experience a visible amount of depression in their lives. Subsequently a very minute difference between the A1 and A2 exists, the guardians have scored 6.39 and PWDs have scored 6.36.

The results would be clearer once the data is revisited in terms of the endorsement percentage

Table-3.33 : ENDORSEMENT PERCENTAGE FOR DEPRESSION SCALE

Item no.	Details of the item	Endorsement Percentage		
		A1 (PWDs)	A2 (Guardian)	Total
3	I am not able to feel good.	49.49	42.39	45.94
6	I often feel that I am not able to do anything.	45.36	34.78	40.07
9	I feel that I have nothing to look forward to.	39.175	35.87	37.52
10	I often fell downhearted and sad.	46.392	47.83	47.11
13	I am not able to be enthusiastic about anything.	37.113	41.30	39.21

22	I have difficulty in taking initiative fir any new task.	**64.95**	**57.61**	**61.28**
26	I feel depressed and sad.	**55.67**	53.26	54.47
27	I feel that I am losing interest in almost everything.	45.36	44.57	44.96
31	I feel I am not worth as person.	43.30	32.61	37.95
33	I have no expectations/hop from the future.	41.24	34.78	38.01
37	I feel that my life is meaningless.	27.84	33.70	30.77
38	I am not able to handle/control my feelings	48.45	45.65	47.05
42	I often have crying bouts without any good reason.	20.62	36.96	28.79
44	Often I want to be alone.	32.99	36.96	34.97
48	I feel unwell.	38.14	46.74	42.44

The table 3.33 clearly shows that the overall endorsement is highest only for the item number 22, i.e. 61.28%, which states that ***"I have difficulty in taking initiative for any new task".*** This is followed by item number 26 in which the endorsement percentage of PWDs is high as 55.67, the item states that ***"I feel depressed and sad"***.

B.II. (iii) Stress

Stress is a psychological and physical response of the body that occurs whenever we try to adapt to changing conditions, whether those conditions be real or perceived, positive or negative. Although everyone has stress in their lives, people respond to stress in different ways. Some people seem to be severely affected while others seem calm, cool, and collected all the time. Regardless, we all have it. It's also important to

note that there are two types of stress, Eustress (good stress) and Distress (not so good stress).

Stress may be defined as "a state of psychological and / or physiological imbalance resulting from the disparity between situational demand and the individual's ability and / or motivation to meet those demands."

Dr. Hans Selye, one of the leading authorities on the concept of stress, described stress as "the rate of all wear and tear caused by life."

Stress can be positive or negative. Stress can be positive when the situation offers an opportunity for a person to gain something. It acts as a motivator for peak performance. Stress can be negative when a person faces social, physical, organisational and emotional problems.

It is stated that mental disorders termed as Common Mental Disorders (CMDs) are most prevalent among those with the lowest material standard of living, especially among those with a long term experience of poverty (Weich & Lewis, 1998). Moreover, the descriptive models of persons with common mental disorders have been described in a number of studies and poverty and socio-economic problems have been cited as one of the most important factors causing emotional distress (Kuruvilla & Jacob,2007).

Stress schale is loaded on 14 items. The items included poor judgement, a general negative outlook, excessive worrying, irritability, agitation, inability to relax, sleeping too much or not enough, feeling lonely, diarrhea or constipation, nausea, dizziness, rapid heartbeat and social withdrawal.

Table-3.34 : ENDORSEENT PERCENTAGE FOR STRESS SCALE

Item No.	Details of the item	Endorsement Percentage		
		A1 (PWDs)	A2 (Guardian)	Total
4	I find it difficult to relax	30.9	**32.61**	31.77
5	I feel that I get upset easily	61.9	**64.13**	62.99
8	I find myself getting restless if delayed in anyway	82.5	**83.7**	83.09
12	I feel that I am rather touchy	64.9	**57.61**	61.28
16	I find as I am getting more irritable	47.4	**45.65**	46.53
17	I find it hard to calm down after getting upset	57.7	**65.22**	61.48
19	I find that it is difficult for me to tolerate any interruptions in whatever I am doing	63.9	**63.04**	63.48
23	I find myself getting agitated in everything	59.8	**42.39**	51.09
29	I am slow to respond	57.7	**64.13**	60.93
30	I feel extremely upset if exposed to events that remind me of similar stressful event.	74.2	**73.91**	74.07
36	I have repeated unwanted memories of the stressful event.	53.6	**50.00**	51.80
40	Often my mind goes blank	22.7	**30.43**	26.56
43	The stressful events cause problems in my relationship with other people	59.8	**58.7**	59.24
46	I have difficulty in concentrating	46.4	**52.17**	49.28

Table 3.34 depicts mean score for stress as 7.88. When compared to total score of 14 it does not indicate much level of stress experienced by respondents. PWDs and Guardians share almost the same value of

stress i.e. 7.83 and 7.93 respectively. The endorsement percentage for each item is given in table 3.34:

The highest overall endorsement percentage (83.09) is for item number8 which states that "***I find myself getting restless if delayed in anyway***" this signifies uneasiness. Closely followed by this is endorsement percentage of item no.30 (74.07) which states that ***"I have repeated unwanted memories of the stressful event.***"

The next endorsement percentage is that of item no.19 (63.48) and item no.5 (62.99) which pertains to *I find that it is difficult for me to tolerate any interruptions in whatever I am doing* and *I feel that I get upset easily.* This fairly high endorsement percentage gives significant stress signal with respect to both PWDs and guardians.

Phase B.

Section III- RELATIONAL WORLD

Different theorists have emphasized on various aspects of self-object relations. For **Kernberg (1984**) self-object is representation of parents in the child's mind. **Laing (1990)** proposes that many instances of mental illness are primarily a result of a lack in basic security of the self. We all have two worlds of relationship**: the internal world and the external world**. How we relate to the external world depends upon the internally construed world of relations. This self-other construing can be understood in a nonthreatening way by projective technique or tests where there is little play of social desirability. In the present research, relational world has been explored as self-other relatedness. This relational construing of the self is measured with the help of **Circle**

technique (Thrower, Bruce and Walton, 1982). It focuses on how one construes one's own self and significant others in his/her life space.

The obtained data from Circle technique (Thrower, Bruce and Walton,1982) is qualitative in nature and has a number of dimensions viz. presence of self, centrality, autonomy, size as well as perception of significant others which are being taken here one by one.

B.III. (i) Presence of Self

Presence of self in life space indicates the development of self in life space. The perusal of the figure reveals that they are themselves in their life space. It is clear from the figure that substantial number of subjects 40.98% showed the presence of self in their life space. The trend is not similar for PWDs and Guardians.

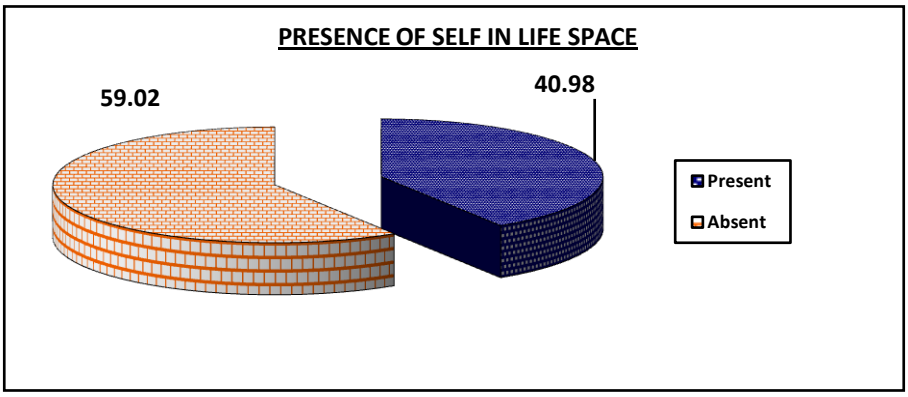


Figure – 3.16(A): Presence of Self

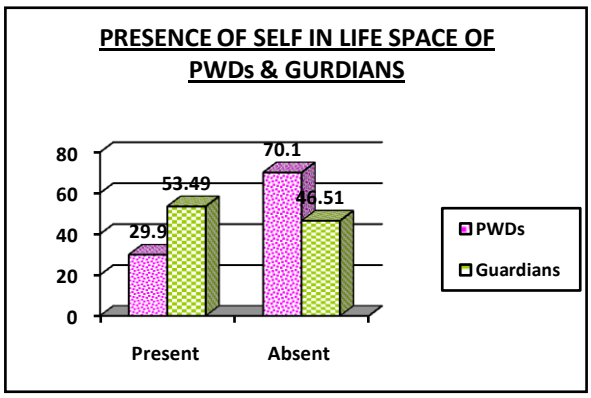


Figure – 3.16(B): Presence of Self

Only 30% PWDs see themselves in their life spaces. On the contrary approximately half of the guardians-53.49% finds themselves in their life spaces.

B.III. (ii) Centrality of Self

It refers to the importance of one's self in the perceived life space. The obtained data on circle technique reflects that for the majority of subjects self is placed at periphery. This leads to the inference that others are given more weightage in their life space. 92% have placed themselves at periphery as only 8% acquire central and dominant position in their life space. This denotes inadequacy of self. The significant others do figure out here, however, they are kept at one up position and self-engulfed with negativity, inadequacy and inferiority is placed at the periphery.

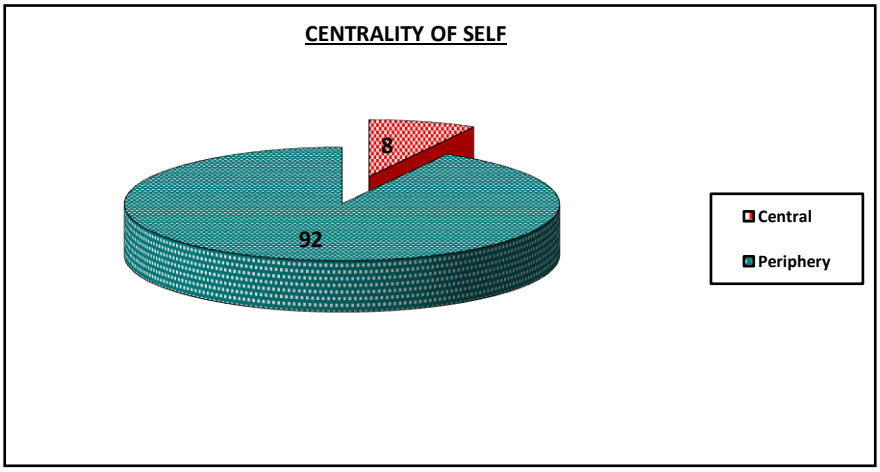


Figure – 3.18(A) : Centrality of Self

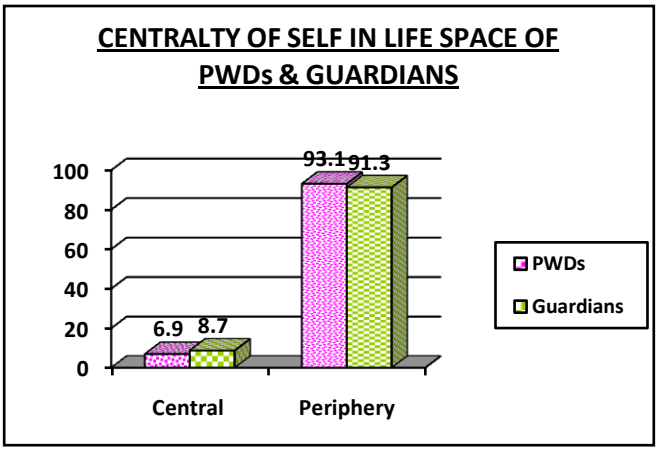


Figure – 3.18(B): Centrality of Self

With reference to the PWDs & guardians data shows that both of them placed themselves at periphery, (93.10% PWDs and 91.3% guardians).

B.III. (iii) Size of Self

The data was also seen for central placement as substantial evidence for the dimension of centrality of self. Size of self, denotes the dominance of self in relation to others. This dimension indicates whether the self of the person in relation to others is more important, less important or equally important.

The picture that emerges from the figure implies that self is perceived both as smaller than others as well as equal to others and only 69.61% of respondents perceive their self to be dominant than others which reveals that respondents either have an equally important self-image when seen in relation to significant others or have a weak and inferior self-image.

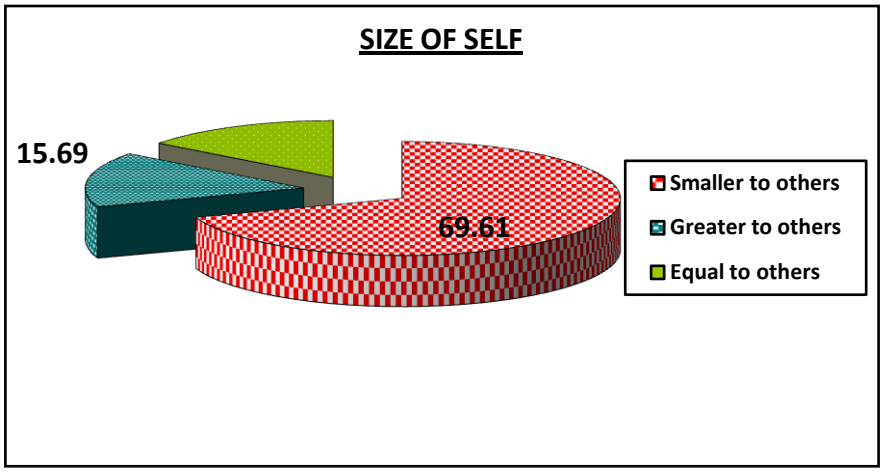


Figure – 3.19(A) : Size of Self

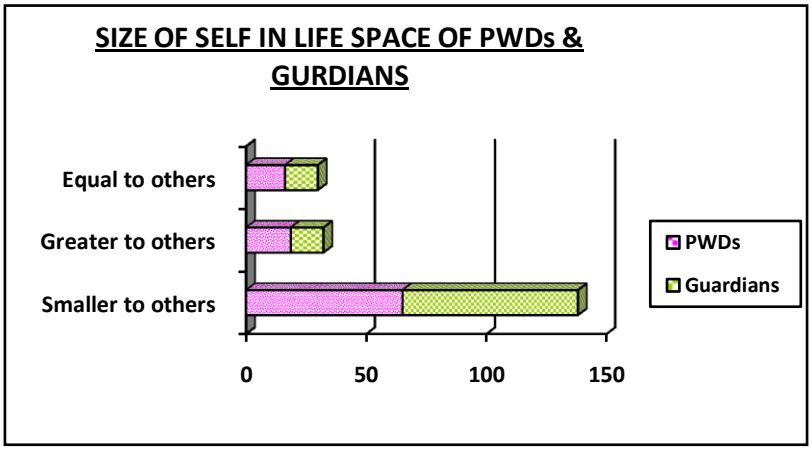


Figure – 3.19(B) : Size of Self

The PWDs see themselves as an inadequate, subservient person in terms of power position not completely in-charge of their lives. Significant others occupy a greater position in their life space as majority of them placed themselves smaller than others i.e. 65.12%. Unfortunately 72.88% guardians believe in the same line.

B.III. (iv) Number of Significant others' emerged

With reference to Significant others that have emerged father/mother, wife/husband, elder brother and son to have acquired an important place in the life space of respondents. The data can be reviewed in terms of the extent of support:-

i. Number of significant others

Category	PWDs	Gaurdian	Total
1_2	80	20	8.20
3_4	53.52	46.48	77.60
5_6	34.62	65.38	14.21

The number of people who emerged as significant others in the life space were classified in 3 categories i.e. 1-2,3-4 and 5-6 members.

From the table it is clear that 77.60% respondents identified 3-4 significant person in their life space followed by 14.21% who have a larger number of 5-6 members and 8.205 report lesser support with 1-2 significant others in the life space.

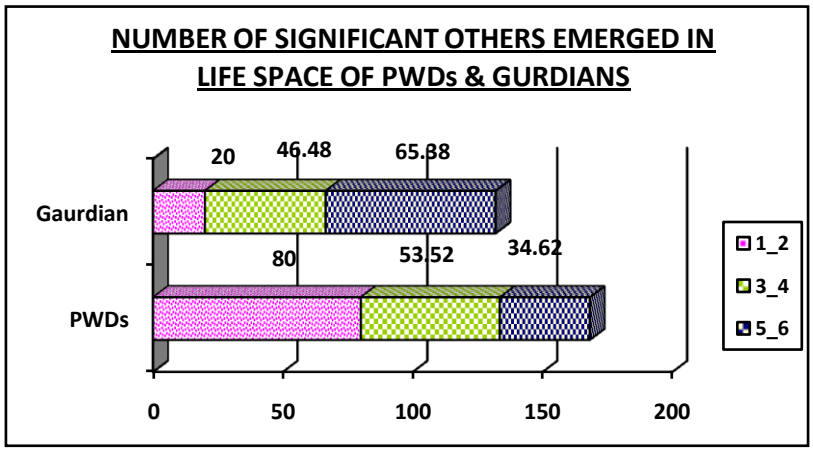


Figure – 3.20 : Number of Significant others

ii. The details of the target person

Further it seems imperative to identify the details of significant others who have emerged in the life space of PWDs & Guardians.

The number of significant others reflect the extent of perceived social support. The graph below shows that among the significant others

who have emerged there are people from family of procreation and family of origin besides the in-laws and friends.

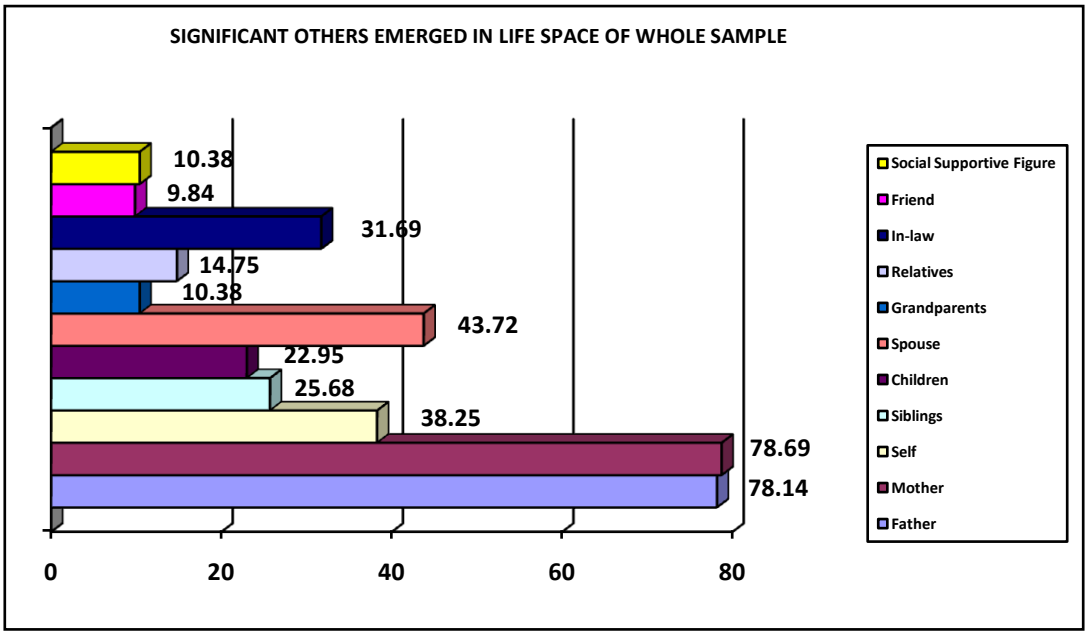


Figure – 3.21(A) : Significant others

In the significant others emerged father & mother have the highest incidence (78.14% & 78.69% respectively) followed by spouse & self (43.72% & 38.25& respectively).

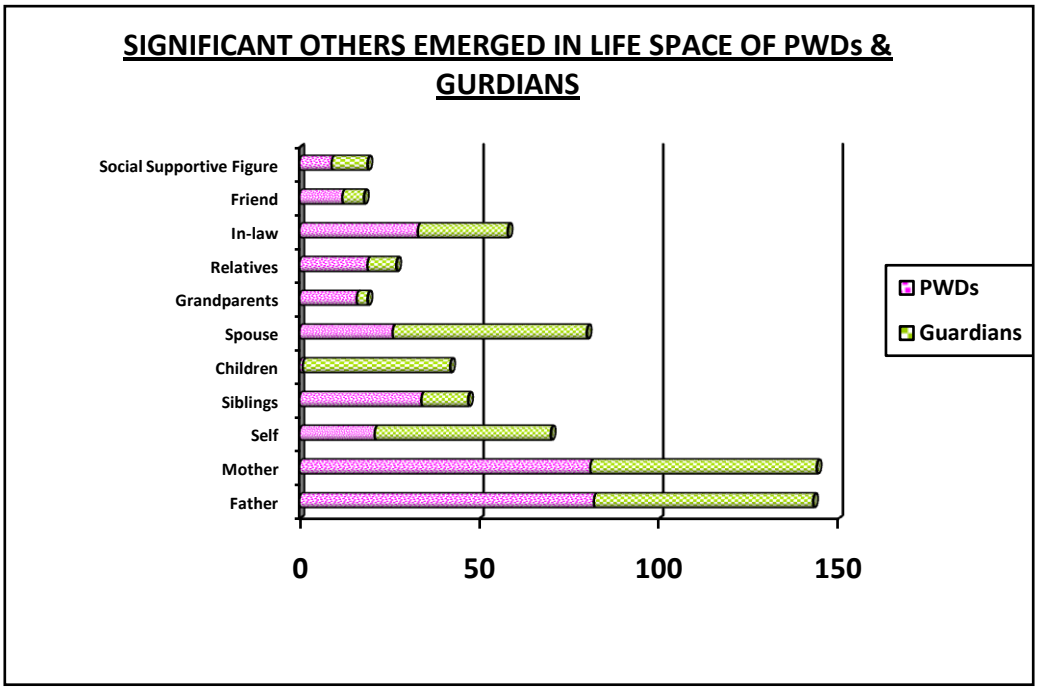


Figure – 3.21(B): Significant Others

The major observations pertaining to self-other relatedness in terms of circle technique are as follows:-

- The self was found to be present more in takers/Guardians in comparison to PWDs.
- However placement of self is at periphery. Thus inadequate self-image is marked.
- Mother & father have emerged as the most important significant other in the life space of PWDs & guardians.

CHAPTER-4

SUMMARY AND SUGGESTIONS

SUMMARY AND SUGGESTIONS

1. About 15% of the world's total population lives with some form of a disability, out of which 2-4% population experiences significant difficulties in functioning. This global estimate for disability is on the rise due to population ageing and the rapid spread of chronic diseases, as well as improvements in the methodologies used to measure disability.
2. **Disability** is a "restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being". Examples of disabilities include difficulty in seeing, speaking or hearing, learning difficulty in moving or climbing stairs, difficulty in grasping, reaching, bathing, eating, and toileting etc.
3. Paradoxically people with disabilities face barriers in accessing the health and rehabilitation services they need in various settings. The present study deals with a specific form of disability that is cerebral palsy. **Cerebral Palsy** is considered as a neurological disorder caused by a non progressive brain injury or malformation that occurs during the brain development of the child. Cerebral Palsy primarily affects body movement and muscle coordination.
4. Symptoms of Cerebral Palsy include difficulty in both gross and fine motor tasks such as writing, balancing, walking and other involuntary movements.
5. People with disabilities require interventions to overcome difficulties that they face in terms of environmental and social barriers.

6. Unfortunately the voices of the disabled citizens seldom reach the policy makers. Disability and development of the PWDs is somehow still experiencing huge gaps between inception of a policy and its implementation.

7. The status of inclusion programs in the rural and somewhat urban areas of Uttar Pradesh is very poor. The programs with inclusive paradigms are hardly present in the state and if at all they exist, there are no follow up provisions of such programs to validate the efficacy of the inclusivity.

PURPOSE OF THE STUDY

The study had twin purposes which were studied in two phases, Phase A and Phase B. In Phase A, the study explored the efficacy of the RCBR[2] project on the PWDs perception of self and the world in Deva Block, District Barabanki. In Phase B, an attempt was also made to explore the health perceptions and mental health status of challenged people and their caregivers and to explore the self other relatedness of the challenged people from Deva Block of Barabanki District.

DESIGN OF THE STUDY

The present study has been conducted in two phases, Phase A and Phase B, wherein Phase A serves as a follow up of an inclusion intervention program on Rural Community based rehabilitation and Phase B is an exploratory research design with an ex post facto orientation to explore the health perceptions, and mental health status and self other relatedness of the PWDs.

Sample

[2] RCBR: Rural Community Based Rehabilitation

In the Phase A the study explores the efficacy of Rural Community Based Rehabilitation Project with sample of 98 Persons with disabilities and in the Phase B an attempt to explore the health perceptions and mental health status of challenged people and their caregivers with 98 PWDs and 100 Caregivers.

The present study comprised of 65% of males and 35% of females in the total research sample. -

Methods

The major method of the present study was conducted in two phases:

PHASE A: Efficacy of the Inclusion Intervention "Rural Community based Rehabilitation Program for PWDs in Deva block, District Barabanki" was explored with the help of a self developed efficacy schedule.

PHASE B: Health perceptions, Mental Health status and self other Relatedness were measured through:

Status of Self Other Relatedness the second phase utilizing an Ex-post facto design with an exploratory orientation sought to obtain the health perceptions and Mental Health status of both the PWDs and their caregivers. The health perceptions were explored with the help of a self developed Health perceptions schedule loaded on the dimensions of health awareness, mental Health perceptions, perception of disability and substance dependence. Mental Health status has been explored with the help of Anxiety Depression stress scale (Bhatnagar, Srivastava, Singh, Mishra, Sadaf and Srivastava, 2011)finally the

relational world of the PWDs was explored in terms of self other relatedness through circle technique.

RESULTS

* Major observations of the Phase A of the study, i.e efficacy of the Inclusion Intervention RCBR program for PWDs in Deva block, Barabanki District, are as follows:

  - The selfhood shows a definite change in the perception of PWDs, as a result of intervention on inclusion wherein the self perception prior to the inclusion intervention generated responses largely loaded on negativity, inadequacy and inferiority.
  - Post intervention program undertaken by SPARC India, the respondent's report of noticing a positive change in their family and society and they are being accepted by other people in the society with respect and dignity.
  - The findings state that there has been a noteworthy change in the attitude of PWDs towards their lives and there was a felt increase in the self esteem and self confidence, post inclusion intervention program.
  - Altogether the respondents gave a very positive response towards the benefits received from the program. It was found that all the beneficiaries, in some or the other way were benefitted and supported by the inclusion program carried out by SPARC-India.

PHASE B – Major observations of Health Perception are as follows:

Section (B-I) i: Health Awareness

Major observations regarding the first dimension of Health perceptions are as follows:

- Unfortunately, 21% of the subjects did not have awareness about the concept of health. Moreover, it was PWDs who had lesser awareness as compared to their caregivers.
- Health was understood by the PWDs (a1) and caregivers (a2) as absence of illness, weakness or inability to work. Among the correlates, Nutritious diet emerged as an essential component of health by both the PWDs and their caregivers.
- Doctors and primary health centers emerged as the main source of information about health. 80.19% of PWDs are aware about infectious diseases.

Section (B-I) ii: Mental Health Perception

With reference to the second dimension of Mental Health Perception, following inferences were drawn:

- Semantic of Happiness is construed as completeness of any work and achievements by PWDs.
- Nutritious diet was considered as one of the major components of a mentally healthy person by more than 50% of the subjects. Both the PWDs (a1) and Caregivers (a2) responded similarly and described mental health as proper functioning of brain and its importance.
- The form of coping used to deal with negative emotions- anxiety and anger- is predominantly negative (active negative).
- Interestingly, most of the PWDs (41.24%) report of being happy at most of times as compared to their caregivers who in term reported a sad mood predominantly.

Section (B-I) iii: Perception of Disability

Major observation regarding the third dimension of Phase B i.e Perception of Disability is stated below:

- Both PWDs and caregivers carry the same opinion towards the rights of persons with disability. Also, they strongly recommend the participation of Person with disabilities in social activities.
- Independence is perceived as earning through any possible source viz., small business, job, farm activities, etc.
- Another very interesting finding is that though both the PWDs and the caregivers feel negative about disability, yet they perceive and think positive about the person with disability. Moreover, PWDs feel more indifferent about their disability.
- Government facilities and reservations have emerged as some most essential plans of PWDs. On the whole they show a poor awareness about health, supporting the hypothesis that "the PWDs would have lower awareness regarding health perceptions as compared to their guardians".

Section (B-I) IV: Substance Dependence

- Unfortunately, both PWDs (a1) and Caregivers (a2) are very heavily dependent on the toxins. Also, the heavy consumption of these toxins by caregivers encourages the PWDs for depending on the same.

Section (B-II) Mental Health Status

The observations regarding the anxiety, depression stress scale are being given below:

- There seems to be a very minor difference existing between PWDs (a1) and Caregivers (a2) for their three dimensions wherein guardians are slight ahead of their counterparts in terms of mean scores in all three dimensions of anxiety, depression and stress. Somewhat supporting the assumption that
- The findings very clearly reflect that the respondents are more sensitive and aware of their bodily symptoms that they experience due to anxiety in their daily lives and their disclosure for the same is also very high.
- PWDs and the caregivers share almost the same level of stress.

Section (B-III) Relational World

With reference to the third section of Phase B viz. Relational World, the following inferences were drawn:

- The self was found to be present in the life spaces of substantial number of respondents, however, they seemed to place others ahead of them in life and therefore, self is placed at periphery. More of the PWDs seem to be at the periphery as compared to their caregivers. This leads to the inference of inadequacy of self and that others are given more weightage in their life spaces.

    5. Parents (both mother and father) have emerged as the most important 'Significant others' in the life spaces of the respondents, followed by spouse and self. The fusion is seen in some cases and hence the assumption is partially supported that "The self other relatedness would show more of a fused/enmeshed relationship in comparison to other types of relationships."

IMPLICATIONS

The government has shown concern for Persons with disabilities and has even formed a separate department under the Ministry for their rehabilitation. However, the following are the areas of concern:

- The mindset of the society/ families has to change from rehabilitation to rights based.
- There is a need to design skill training programs for PWDs to make them independent which also includes financial independency.
- The society/ NGOs should come in a big way to provide inclusive environment for development of Persons with Disabilities in various aspects of life.
- There is a need to design Health Intervention Programs for PWDs and caregivers both in urban and rural areas, to increase their awareness about various diseases health issues and importance of mental health.
- In all programs, right from school, the personality development programs should be given importance for the development of self esteem of PWDs for which it is important to impart education to the peer group as well as caregivers.
- The statutory authorities/ implementing authorities should ensure pragmatic implementation of the existing laws and policies to enable Persons with disabilities to live dignified life.

SUGGESTIONS

- Academic institutions, universities and government should promote “action research” on different aspects of PWDs/parents as well as the caregivers.

- Awareness about the plight of PWDs and principle of universal design should be followed for easy accessibility and their inclusion.
- Different age groups can be taken for the assessment of mental health coping and awareness of mood states sadness, anxiety and stress levels.
- This study could not take in its gamut PWDs with various kinds of disability. This could be a starting point for other studies particularly the follow ups of other inclusion and Rehabilitation studies.

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APPENDICES

APPENDIX-A

PERCEIVED HEALTH SCHEDULE

मनोवैज्ञानिक प्रयोगशाला लखनऊ विश्वविद्यालय, लखनऊ

निर्देश : "हम आपकी रोजमर्रा की जिन्दगी से जुड़ी कुछ बातें जानना चाहतें हैं। यकीन रखिए आपके जवाब हम तक ही रहेंगे। हम आपसे कुछ प्रश्न पूछेंगे, उनके जवाब आप पूरी ईमानदारी से दें।"

1. सेहत अथवा स्वास्थ्य से आप क्या समझते है?

.....

2. सेहतमंद आदमी कैसा होता है ?

.....

3. अच्छी सेहत के लिए क्या जरूरी है ?

.....

4. दिमागी तौर पर सेहतमंद कौन होता है ?

.....

5. खुशी से आप क्या समझते है ?

.....

6. खुश होने पर आप क्या करते है ?

.....

7. दुःख से आप क्या समझते है ?

.....

8. दुःखी होने पर आप क्या करते है ?

.....

9. नीचे दिए गए चेहरों में हर चेहरा मन का एक भाव बताता है? ज्यादातर समय आप इनमें से किस चेहरे में रहते है ? उस चेहरे पर निशान लगाए।

खुशनुमा

दुःखी

गुस्सा

डर

सपाट

अनमना/बोर

मालूम नहीं

10. चिंता या परेशानी से आप क्या समझते है ?

.....

11. चिंता या परेशानी होने पर आप क्या करते हैं ?

.....

12. सेहत के बारे में आपको कहां से जानकारी मिलती है ?

.....

13. अब तक कौन-कौन सी बीमारी आपको हुई है ?

.....

14. बीमारी क्या होती है ?

.....

15. आपके यहां कौन-कौन सी बीमारियां अमूमन होती है ?

.....

16. खुद को ऐसी परेशानी होने पर क्या करते है ?

.....

17. आपके हिसाब से मन ठीक न रहना, बहुत परेशान रहना, अधिक डरना, अजीब-अजीब हरकतें करना आदि बीमारियाँ क्यों होती हैं ?

.....

18. इनके होने पर आप क्या करते है ?

.....

19. अच्छी दिमागी सेहत के लिए क्या जरुरी है ?

.....

20. जब परेशानी आती है तो आप क्या करते हैं ?

.....

21. काम के बीच की थकान को खत्म करने के लिए क्या करते हैं?

.....

22. क्या आप कोई तम्बाकू, बीड़ी, शराब, सिगरेट लेते है या घर में कोई लेता है ?

.....

23. अमूमन गुस्सा आने पर आप क्या करते है ?

.....

24. आपकी निजी जिन्दगी में क्या कुछ ऐसे लोग है जिन्हें चलने-फिरने, बोलने, सुनने या दिमागी कार्य करने में किसी प्रकार की दिक्कत है ? हाँ /नहीं

.....

25. इस प्रकार की दिक्कत या कमी के बारे में आप क्या महसूस करते हैं ?

.....

अब हम इन लोगों से जुड़े अधूरे वाक्य देंगे जिन्हें सुनकर आपके दिमाग में जो बात सबसे पहले आये, वह बताइये : (यदि समझ में ग आए तो बताएं उन लोगों के बारे में जिन्हें चलने, फिरने, बोलने, सुनने या दिमागी काम करने में दिक्कत है।)

26. ऐसे लोग

.....

27. ऐसे लोगों के प्रति आपके गांव के लोगों का नजरिया

.....

28. इन कमियों के साथ रहने वाले (विकलांग)लोगे के अधिकार

.....

29. इनका अपने पैरों पर खड़ा होना

.....

30. इनकी समाज में भागीदारी

.....

31. अब बताइयें, इन कमियों/दिक्कतों/विकलांगता वाले लोगों के लिए आपके अनुसार

(**अ**) क्या- क्या काम ये कर सकते हैं?

.....

(ब)क्या- क्या काम ये नही कर सकते हैं?

.....

(स)क्या- क्या काम ये नही कर सकते हैं?

.....

32. इनके लिए क्या-क्या होना चाहिए और क्या-क्या नहीं होना चाहिए?

.....

APPENDIX-B

ANXIETY DEPRESSION STRESS SCALE (ADSS)

मनोवैज्ञानिक प्रयोगशाला लखनऊ विश्वविद्यालय लखनऊ

निर्देश : ""हम सब अपनी जिंदगी में चिंता तनाव व दुःख अक्सर महसूस करते है। हम आपसे आपके रोजमर्रा की जिंदगी में महसूस किए जाने वाले चिंता तनाव व दुःख से सम्बन्धित कुछ प्रश्न पूछेगें। यदि आपको लगता है कि आप अक्सर ऐसा महसूस करते है तो अपना जवाब हाँ में दीजिए।आपके जवाब गोपनीय रखें जाऐगे। अतः ईमानदारी से उत्तर दें। "

1. मुझे अपने मुँह सूख जाने के बारे में पता चल जाता है। हाँ /न
2. सांस लेने में दिक्कत महसूस करते हैं (जैसे सांस का तेज चलना बिना काम किए सांस में दिक्कत होना)। हाँ /न
3. कुछ भी अच्छा महसूस नहीं तक पाते है। हाँ /न
4. मुझे आराम करने में दिक्कत होती है। हाँ /न
5. मुझे लगता है कि मैं बहुत जल्दी परेशान हो जाता हूँ। हाँ /न
6. अक्सर ऐसा महसूस होता है कि मैं कुछ नही कर सकता। हाँ /न
7. अक्सर मुझे ऐसा लगता है कि मेरे हाथ-पैर कांपते है(पैरों में जान नहीं है पैर जवाब दे रहे हैं)। हाँ /न
8. किसी भी प्रकार की देरी हो जाने पर बेचैनी होने लगती है। हाँ /न
9. मुझे ऐसा लगता है कि जीवन में कुछ बचा ही नहीं है। हाँ /न
10. मुझे अक्सर ऐसा लगता है कि दिल बैठा जा रहा है और मैं दुःखी हूँ। हाँ /न
11. मुझे अक्सर ऐसा महसूस होता है कि बेहोशी आ रही है। हाँ /न
12. मुझको अधिकतर बातें जल्दी बुरी लग जाती है। हाँ /न
13. मुझे किसी भी चीज में जोश नहीं आ पा रहा है। हाँ /न
14. मुझे काम न करने और गर्मी न होने पर भी अत्यधिक पसीना आता है(जैसे हाथ-पैर पसीने में भीग जातें है) । हाँ /न
15. मुझे बिना किसी ठोस वजह के डर लगता है। हाँ /न
16. मैने पाया जैसे मै बहुत चिड़चिड़ा हो गया हूँ। हाँ /न
17. मैने पाया कि किसी बात से परेशान होने के बाद मुझे शांत होने में मुश्किल होती है। हाँ /न
18. मुझे निगलने में दिक्कत होती है। हाँ /न
19. मैने पाया कि मेरे काम में टोका-टोकी होने पर उसे बर्दाश्त करने में मुझे परेशानी होती है। हाँ /न
20. मैं उन चीजों के बारे में परेशान रहता हूँ जिनमें मै मारे घबराहट के कहीं कुछ गड़बड़ न कर दूँ और मेरा मजाक न बन जाएं। हाँ /न
21. मैं बहुत ज्यादा घबराहट और बेचैनी महसूस करता हूँ। हाँ /न
22. काम को शुरू करने में पहल करने में दिक्कत होती है। हाँ/न
23. मैं अपने आप को बात-बात में उत्तेजित पाता हूँ। हाँ /न
24. मैं सिर गर्दन और पीठ के दर्द से परेशान रहता हूँ। हाँ /न

25. मै कमजोरी महसूस करता हैं और जल्दी थक जाता हूँ। हाँ /न
26. मै दुःखी और निराश महसूस करता हूँ। हाँ /न
27. मै महसूस करता हूँ कि मेरा किसी चीजकाम में मन नही लगता है। हाँ /न
28. मैं अपने दिल की धड़कन की तेज होना महसूस करता हूँ। हाँ /न
29. मुझे किसी बात का जवाब देने मे समय लगता है। हाँ/न
30. किसी भी ऐसे काम या घटना का सामना करने में मुझे बहुत दिक्कत होती है जो मुझे वैसी ही किसी बीती हुई परेशानी की याद दिलाती है। हाँ /न
31. मै खुद के बारे में बहुत बेकार महसूस करता हूँ। हाँ /न
32. मुझे लगता है कि हाथ-पैरों की उंगलियाँ सुन्न हो रही है और उनमें झनझनाहट हो रही है। हाँ /न
33. मुझे आगे आने वाले कल से कोई उम्मीद नही है। हाँ /न
34. मै पेट दर्द और बदहजनी से परेशान रहता हूँ। हाँ /न
35. मुझे जल्दी-जल्दी पेशाब करने जाना पड़ता है। हाँ /न
36. न चाहते हुए भी मुझे बार-बार बुरी घटनाओं की याद आ जाती है। हाँ /न
37. मुझे लगता है कि मेरी जिन्दगी का कोई मतलब नही है। हाँ /न
38. मै अपने गुस्से पर काबू नही रख पाता /आपा नही रहता। हाँ /न
39. मुझे डरावने सपने आते है। हाँ /न
40. अक्सर मुझे ऐसा लगता है कि मेरा दिमाग खाली हो गया। हाँ /न
41. मुझे सीने में दबाव /भारीपन महसूस होता है। हाँ /न
42. बिना किसी कारण के अक्सर मेरी रुलाई फूट पड़ती है। हाँ /न
43. उस घटना के बाद से दूसरे लोगों के साथ मेरे रिश्तों में खटास आ गई है(तनाव या परेशान करने वाली घटनाओं के बाद में कुछ समय तक मेरे रिश्तों में खटास आ जाती है) हाँ /न
44. अक्सर अकेले पड़े रहने का मन करता है। हाँ /न
45. अक्सर मेरी आंखों के सामने अंधेरा सा हो जाता है या धुंधलापन छा जाता है। हाँ /न
46. मुझे ध्यान लगाने में दिक्कत होती है। हाँ /न
47. अक्सर मेरा जी मिचलता है। हाँ /न
48. तबीयत गिरी-गिरी सी रहती है। हाँ /न
49. मुझे नींद में खर्राटे आते है। हाँ /न
50. कुछ ही समय बाद मै भूल जाता हूँ। हाँ /न

APPENDIX-C

CIRCLE TECHNIQUE

मनोवैज्ञानिक प्रयोगशाला लखनऊ विश्वविद्यालय, लखनऊ

निर्देश : " यह गोला आपके जीवन क्षेत्र / जिन्दगी का दायरा है। हम आपको छोटी बड़ी सभी प्रकार की बिंदीनुमा गोले दे रहे है। इन बिंदियों की सहीयता से आप खुद को तथा अपनी जिंदगी के महत्वपूर्ण लोगों को (जो आपकी जिंदगी में बहुत मायने रखते है) उनको दिखाएँ। ये बिंदीनुमा गोले छोटे भी हो सकते है (o) और बड़े भी हो सकतें है (O)। यह इस बात पर निर्भर करेगा कि अमुक व्यक्ति आपके जीवन में कितना महत्वपूर्ण है व कितना मायने रखता है। यदि किसी व्यक्ति की मृत्यु हो चुकी है लेकिन वह आज भी आपकी जिंदगी में बहुत महत्वपूर्ण है, तो उसको भी आप इस गोले में दिखा सकते है। प्रत्येक गोला किस व्यकित को दिखा रहा है उसका नाम अथवा रिश्ता अवश्य बताएं। आपके द्वारा दी गई यह जानकारी हमारे पास ही रहेगी तथा गोपनीय रखी जाएगी। "