

**Role of support for caregivers of people  
with severe mental disorders in  
Uttarakhand, India**

**PRERANA SINGH  
INDIA**

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# **ROLE OF SUPPORT FOR CAREGIVERS OF PEOPLE WITH SEVERE MENTAL DISORDERS IN UTTARAKHAND, INDIA**

A thesis submitted in partial fulfilment of the requirement for the degree of Master of Public Health

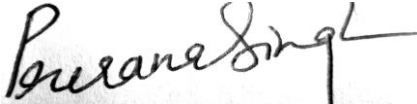
By

Prerana Singh

India

**Declaration:** Where other people's work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.

The thesis "Role of support for caregivers of people with severe mental disorders in Uttarakhand, India" is my own work.

**Signature:** 

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## Glossary

**Caregiver burden:** "Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness" (1).

**Coping:** Coping is defined as "any response to external life strains that prevent, avoid, or control emotional distress" (2).

**Essential psychotropic drugs:** These are medicines that satisfy the priority mental health care needs of a population. They are selected with due regard to public health relevance, and based on evidence of their efficacy, safety and comparative cost-effectiveness. They can be used for the treatment of symptoms of mental disorders, to shorten the course of many disorders, reduce disability and prevent relapse (3).

**Mental health:** A state of complete physical, mental and social wellbeing, and not merely the absence of disease (4).

**Mental Illness:** Mental illness is defined as- "the health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning" (5).

**Objective burden:** The objective burden is defined by the observable challenges and effects on family due to caregiving for a relative with severe mental illness. The objective burden consists of change in daily routine of household activities, financial problems, constraints on personal and social relations (6).

**Psychiatrist:** A psychiatrist is a medical doctor specialized in psychiatry (Mental health and illness) with at least two years of post-graduate training in psychiatry (3).

**Severe mental disorders:** severe mental disorders are marked by severe behavioural difficulties, distorted thinking and feelings. These are the conditions considered mental illness by environment and are primarily schizophrenia, bipolar disorder and brief psychoses (7).

**Subjective burden:** The subjective burden results from the objective burden and is the personal appraisal of the situation by the caregiver. It is the emotional distress experienced due to the illness of the family member and the burden of caring for him/her (6).

## List of Abbreviations

|        |   |
|--------|---|
| AIDS   | Acquired Immunodeficiency syndrome            |
| BPL    | Below Poverty line                            |
| DMHP   | District Mental health plan                   |
| GOI    | Government of India                           |
| HCA    | Home Care Advisors                            |
| HIV    | Human Immunodeficiency virus                  |
| IEC    | Information education communication           |
| MHAP   | Mental health action plan                     |
| NMHP   | National mental health program                |
| PHC    | Primary health centre                         |
| PWMDS  | People with mental disorders                  |
| PWMI   | People with mental illness                    |
| PWSMDs | People with severe mental disorders           |
| SMD    | Severe mental disorders                       |
| SMHA   | State Mental Health Authority                 |
| SMHP   | State mental health plan                      |
| TB     | Tuberculosis                                  |
| Ukhfws | Uttarakhand health and family welfare society |
| WHO    | World health organisation                     |

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## **Abstract**

**Background:** 70 million out of 1.28 billion people in India suffer from mental disorders out of which 20 million suffer from severe mental disorders. 90% of the people with mental disorders live with their families who act as primary caregivers. The mental health program failed to address the needs of the family caregivers of people with severe mental disorders (PWSMDs) in Uttarakhand.

**Objective:** To identify influencing factors for burden of caregiving, analyse the potential role of support for caregivers and provide recommendations to concerned authorities, to develop support interventions for caregivers of PWSMDs in Uttarakhand.

**Methodology:** The literature review was done using adapted family caregiving burden framework from Pallet 1990.

**Findings:** Women are the primary care giver for family member with SMDs in Uttarakhand and have social, financial and emotional burden. Socio economic status, poor awareness and inadequate mental health and social services add to the burden of caregiver. Religion is a strong influencing factor in the state. Stigma and discrimination related to mental disorders limit access to support from society. The state mental health program lacks specific intervention for addressing needs of the caregivers.

**Conclusion:** The inadequate mental health system, poor information and awareness of mental health and stigma affect the burden of caregiving in Uttarakhand.

**Recommendations:** Multi-sectoral collaboration for inclusion of caregivers, mental health awareness to address stigma and strategic plan for funding, recruitment and redistribution of health services is imperative to support the caregivers.

**Key words:** *Mental health, Severe mental disorders, India, Uttarakhand, Caregivers.*

**Word count: 12,047**

## **Introduction**

'No health without mental health' is the key slogan for an attempt to bring global attention to the epidemiological threat of mental illness. The global prevalence of mental or behavioural disorders is 450 million people (8). Government of India estimates show 70 million out of 1.28 billion people, suffer from common and severe mental disorders (9).

As countries plan and frame policies and programs for prevention of mental illness and promotion of mental health, a group often goes unnoticed. These are the family caregivers of people with mental disorders. About 90% of people with mental disorders live with their families in India. They are the undervalued workforce which has the lions' share for caring and management of mentally ill people.

I work with community health and development projects of a non-government organisation in North India. During my work, I often came across families who would hide their mentally ill person, lock them in a room, and sometimes abandon them. I considered such behaviours to be inhuman and wished that families took good care of their mentally ill member.

However, when I had to be the caregiver for a mentally ill family member, it took me off guard. The unexpected responsibility and experience as caregiver, changed my perception towards the families of mentally ill people. Though I worked with a hospital, I struggled to get adequate help in terms of treatment, information and support. The financial, social and emotional pressures of caring made me question – "what can I do? Who can help? Where should I go for assistance?" This gave me the insight to study about why it is necessary to pay attention to caregivers and how they can be helped.

Within this topic of mental health, this thesis focuses on the role of support in assisting caregivers of people with severe mental. My thesis will help in identifying and analysing the barriers faced by caregivers and potential impact of social resources. The recommendations will be shared with the Uttarakhand Ministry of health, policy makers, NGOS and other stakeholders to build supportive interventions for family caregivers of people with mental illnesses.

This thesis has been a learning experience for me, as I was able to understand the multidimensional stress of carers. I could relate to those due to the challenges and stress I felt being a caregiver. I hope to study further about caregivers and their needs in order to make a change and assist them in a good quality life.

# Chapter I: Background information

## 1.1 Overview of the country and Uttarakhand

India, the land of cultures, religions, traditions and diverse landforms has different ethnic and linguistic groups adding to its diversity. As per census 2011, India had a population of 1.28 billion (10) with a population density of 382 per square km and the sex ratio of 943 females per 1000 men. The northern border of India is lined with Himalayas and has China, Nepal and Bhutan neighbouring countries on north. India has Pakistan on the west and Bangladesh and Myanmar on the eastern borders (11). The country is a secular nation and has 29 states and 7 union territories.

**Figure 1: Map of India. (13)**



Uttarakhand is the 27<sup>th</sup> state of India and borders China in the north-east and Nepal to the south-east as neighbouring countries. The Uttarakhand state is subdivided into 13 districts, 78 Tehsils (regions), 95 blocks and 16,828 villages (11,12). It has a population of 10.08 million, of which 7 million live in the rural area and 3 million are residents of the urban area (10). The state is hilly

and the most sparsely populated state in the country with a population density of 189 persons per square kilometre. The sex ratio in the state is 963 females /1000 males (10).

## 1.2 Socio-economic situation

Internationally, the extreme poverty line is defined as an income of less than \$1.25 per day per head of purchasing power parity. In 2012, 21.9% of Indian population lived below poverty line (14). In The state of Uttarakhand had 3.6million people living below poverty line which is 11.26 % of the state population (14). The unemployment rate in country is 8.8% as per 2013 estimates (10). Ministry and Labour unemployment survey in 2010 showed that unemployment rate of 4.6% Uttarakhand. It

showed that more female were employed than male in Uttarakhand (15). There might be a reporting error or a misrepresentation of data in terms of employment rate in Uttarakhand. However, the MLoE report also mentions two other states which have lower unemployment rates in women as compared to men. The report is attached as annex 1 for reference.

### **1.3 Education**

India has a literacy rate of 72.9%, which varies between male (80.84%) and female (64 %). Literacy rate in Uttarakhand is 78.82% with male literacy 87.4 % and female literacy about 70.01% (10,12). As per Indian government, literacy is the ability of a person to read, write and understand in any language. The literacy rate varies between urban regions (84.45%) and rural regions (76.31 %) in Uttarakhand and is higher for men compared to women in both urban and rural regions (10).

### **1.4 Religion**

Hinduism is the dominant religion in India with other religions like Islam, Christianity, Buddhism, Jainism and Sikhism as minority (10). The state Uttarakhand has holy Hindu shrines, and a large number of pilgrims visiting it all year. It is called "Dev Bhumi- Land of Gods", and is famous for its culture and traditions (11). Some people still believe that all sickness is the wrath of angry gods and goddesses. Especially any case of mental disorder is considered the result of supernatural phenomena or punishments for deeds of previous life and treatment is sought from faith based healers, witchcraft and sorcerers. In some parts of rural India, people believe the cause of mental illness is the angry evil spirits or that the sick person had killed a cow during his/her past life (16). However a study in Uttarakhand among caregivers conflicts these studies and highlighted the people were aware that mental illness is a disease and is curable (17).

### **1.5 Health situation**

National disease control centre India reports the triple burden of diseases, viz. communicable, non-communicable and emerging infectious diseases due to geographical and demographical transactions. Major disease burden in India is of diarrhoea, malaria, tuberculosis, chronic obstructive pulmonary disease, heart diseases, maternal and child health issue and

HIV/AIDS. Non-communicable diseases are the leading causes of death in India, constituting 42% of all deaths. Communicable, maternal, perinatal and nutritional conditions constitute another 38% of deaths (18, 19).

India has the highest burden for TB cases in the world with incidence of 2.1 out of 9.2 million cases in the world in 2013 and the estimated prevalence of TB in India is 2.6 million in 2013 (20). Experts estimate that about 2.5 million persons have HIV infection in India. This is nearly 7.6% of the global burden of 33 million cases. More than 1.5 million persons are affected with malaria every year of which 1/3<sup>rd</sup> live in India. More than 300 million episodes of acute diarrhoea occur every year in India in children below 5 years of age (18). Besides the communicable and vector borne diseases, India has shown increasing rise of non-communicable diseases like obesity, diabetes, heart diseases and mental illnesses. Urbanisation and development has given rise to increasing burden of non-communicable diseases in Indian population (19).

Estimated prevalence of mental disorders in India is 65 per 1000 population. This is approximately 70 million people out of 1.28 billion population of India. 1-2% (10 to 20 million) from this 70 million is estimated to be people with severe mental disorders and approximately 5% (50 million) are people with common mental disorders (21, 22). Estimates show that mental illness in India will increase to 15% by year 2020 (8).

There is no national data available for prevalence of mental disorders and over past decades many studies have been conducted to estimate psychiatric morbidity in India. Math and Srinivasaraju (23) in their review of the epidemiology of mental disorders in India showed the variance in psychiatric morbidity (*see annex 2*).

A meta-analysis of 13 epidemiological studies conducted by Reddy and Chandrashekar, yielded an estimated prevalence rate of 5.8% for mental disorders (24). As per analysis, the common disorders were neurotic disorders (2.07%), affective disorders (1.23%), alcohol/drug dependence (0.69%), mental retardation (0.69%), epilepsy (0.44%), schizophrenia (0.27%) and Organic psychosis (0.04%)(22). Mental disorders like anxiety, depression, schizophrenia, epilepsy, psychosis, Alzheimer are prominent in India (24). The absence of recent epidemiological studies and data on mental disorders in India indicates the low importance given to mental health in health system.

## **1.6 Health system**

The Indian health system is decentralised and has a three tier system for implementation. Rural health care has three tiers of sub centre, primary health care centre and community health centre based on the population norms. Urban areas have city hospital, district hospitals and tertiary care hospitals for specialized services in hospitals (25). Federal and state government funds these health facilities and they are run by state governments. Ambulatory services aid in the referral and linkages between the primary health centres and the higher centres.

Private sector plays a major role in health care system in India. More than 80% of the trained health care workers are employed in the private sector in India (26).

The total health expenditure of India in 2011 was 3.9% of GDP. Government expenditure was 30.5% of the total health expenditure, whereas 69.5% was from private sector and out of pocket expenditure. India spends less than 1% of its total health budget on mental health (27). General taxation is the main source of funding for the government expenditure. Uttarakhand has two health insurance schemes – Rashtriya Swasthya Bima Yojna by Ministry of Labour and Employment, Government of India provides hospitalization coverage upto Rs. 30,000 (\$470) to the BPL population (28). The second scheme is Urban health Card for cashless treatment for employees, their families and pensioners of State government (28,29).

## **Chapter II: Problem statement, justification, objectives, research questions and methodology**

### **2.1 Problem Statement**

In India, more than 90% of patients with chronic mental illness live with their families (30). The family caregiver (Parents, spouses, children and siblings) plays multiple roles including taking day-to-day care, supervising medications, taking the patient to the hospital and looking after the financial needs. Aaron and colleagues showed that physical, psychological, social, time and financial burden on caregivers is high, but neglected and limited research is available to define and measure caregiving burden in low and middle income countries (31).

Mathew Tull, Post Trauma Stress disorder expert defines caregiver burden as “a high level of stress that may be experienced by people who are caring for another person (usually a family member) with some kind of illness” (1). Caregivers are even termed as secondary patients, as due to the exhaustive nature of care giving, their mental and physical health is sometimes at stake. They are the unpaid care givers who face the double burden from the patient as well as societal pressures (30). The difficult behaviour and aggressive nature of the person with severe mental disorders leads to poor adherence to treatment, loss of time and work and embarrassment and stigmatisation by the society. In India, the predictors for family caregiving burden vary from the western countries due to cultural variations. The burden is experienced in form of the additional responsibility of caring for a mentally ill person, disruption in family life, financial burden, shame and social isolation (32).

Mental illness is broadly understood in two main dimensions- common mental disorders (CMDs) and severe mental disorders (SMDs). The difference and transition between common mental disorders and severe mental disorders are fluid and is difficult to define (33).

Common mental disorders are mild to moderate depression, substance abuse and anxiety disorders which when presented at primary health care level, often go undiagnosed due to overlapping symptoms. The common mental disorders are strongly linked with social factors (33).

Patel (7) characterized the severe mental disorders (SMD) or psychoses by the marked behavioural difficulties and distorted thinking in his mental health care manual – “Where there is no psychiatrist”. Severe mental disorders are basically three main illness schizophrenia, manic depressive disorder or bipolar disorder and brief psychoses.

The society often has a suspicious, stigmatising and discriminatory attitude toward persons with severe mental disorders due to their difficult behaviours. The neighbours and even relatives look down upon the person with disorder and the caregivers and are avoided by society (34).

Hindustan Times- one of the lead national newspaper in India, published the news in 2010 about mentally ill people being dumped near the tiger reserves in Karnataka. The news reported that caregivers of PWSMDs paid highway truck drivers to do so. Renuka Prasad, in-charge of Gundulpet police station in Karnataka, confirmed this in her statement- "Long-distance truckers are known to pick up the mentally ill, especially women, and rape them before dumping them"(35). This is not how all caregivers cope, but, it sure is an illustration of the extreme stress and inability to cope that caregivers go through in absence of any kind of support in India.

In absence of adequate services and knowledge, seeking treatment from shrines and faith healers or local unqualified pharmacist or practitioners by the caregivers for their mentally ill family members is common practise in Uttarakhand (36). The distance from general health facilities and lack of mental health services, leads to no treatment for person with mental disorders. Caregivers of PWMI have no information about what to do and where to go for help. Studies show that caregivers undergo high level of distress due to caregiving burden and become vulnerable to poor physical and mental health. This state of caregiver is expected to have adverse effects on the patient's health (37).

## **2.2 Justification**

The studies on burden of caring for people with severe mental disorders by their families are limited. One of the studies show lack of support from extended family and society, feeling of guilt, embarrassment and social isolation and discrimination for patient as well as family caregiver of people with severe mental disorders(38).

Researches on stigma and discrimination for PWMDs and their families have been conducted in south and east India. These studies tell in unison, a story of exclusion experienced by both PWMDs and their family members (39, 40, 41, 42). The researches have focussed on evaluating objective burden of caregivers of mental disorders in India, but lack focus on the emotional burden and potential role of support in coping with the burden of caring (43).



The available studies are evaluation reports for family support interventions piloted in few states in India, which have adequate resources and services for mental health. These studies do not apply to Uttarakhand as there is shortage of mental health services and nominal representation of caregivers as recipients, in community based mental health programme in the state. No epidemiological data on mental disorders and no research conducted on burden, coping and support for caregivers, highlights the importance for more research studies in Uttarakhand.

## **2.3 Objectives**

### **2.3.1 General objective**

To analyse the role of support for family caregivers of PWSMDs, in assisting with caregiving burden in order to provide information to policy makers and state government for informed decision making for research, planning and implementation of support interventions for caregivers in Uttarakhand.

### **2.3.2 Specific objectives**

1. To analyse social, financial and emotional burden of caring and coping mechanisms of the family caregivers of PWSMD.
2. To analyse socio demographic factors, social networks and health and social services for caregivers and their influence on caregiving burden of family caregivers.
3. To review evidence based caregivers support interventions in India and other countries in terms of potential to applicability in Uttarakhand.
4. To provide recommendations to Uttarakhand state Government, Ministry of health Uttarakhand, policy makers and NGOs to develop support interventions for caregivers of PWSMDs in Uttarakhand.

## **2.4 Methodology**

The research methodology is a literature review of peer reviewed published and unpublished articles and grey literature on mental health, caregiver support interventions and burden of caregiving. The search engines used for the literature review are Google scholar and Pubmed. Vu library was also used for accessing literatures for this review. Grey literatures like report from ministry of health of Uttarakhand and India,

WHO and NGOs working on mental health in India, news articles and blogs were also used for this study. Articles were also searched using the bibliography of the selected articles.

### 2.4.1 Search strategy

There had not been many researches on the coping mechanisms and social support for caregivers in India. There are limited publications on mental health and caregiving burden in past decade in India. So the articles from 1996 onwards were used for review however the conceptual framework from 1990 has been used for the literature review. The study only used articles published in Hindi and English language. The keywords used for searching the literatures are presented in the table below.

**Table 1: search strategy- sources and keywords.**

| <b>Type of study</b>                                 | <b>Source</b>   | <b>Keywords in combination used for objective 1</b>  | <b>Keywords in combination used for objective 2</b>  | <b>Keywords in combination used for objective 3</b>   |
|--|---|--|--|---|
| Published Peer reviewed.                             | <ul style="list-style-type: none"> <li>▪ Vu library</li> <li>▪ Google scholar</li> <li>▪ Pubmed</li> </ul>  | <ul style="list-style-type: none"> <li>▪ Mental health</li> <li>▪ India</li> <li>▪ Caregivers</li> <li>▪ Caregiving burden</li> <li>▪ Severe mental disorders</li> <li>▪ Coping strategies</li> </ul>  | <ul style="list-style-type: none"> <li>▪ Schizophrenia</li> <li>▪ Severe mental disorders</li> <li>▪ Social capital</li> <li>▪ Mental health and stigma</li> <li>▪ Religion</li> <li>▪ Uttarakhand and mental health.</li> </ul> | <ul style="list-style-type: none"> <li>▪ Support</li> <li>▪ Support groups</li> <li>▪ Social support</li> <li>▪ Stigma</li> </ul> |
| Grey literature<br>Reports<br>Blogs<br>News articles | <ul style="list-style-type: none"> <li>▪ Google</li> <li>▪ WHO</li> <li>▪ Institutional sites – Mohfw, News agencies.</li> <li>▪ NGO reports</li> </ul> | <ul style="list-style-type: none"> <li>▪ Objective burden</li> <li>▪ Subjective burden</li> <li>▪ Financial burden</li> <li>▪ Social burden</li> <li>▪ Emotional burden</li> <li>▪ Stress</li> <li>▪ Problem focused coping</li> <li>▪ Emotion based coping</li> </ul> | <ul style="list-style-type: none"> <li>▪ Gender And Mental health</li> <li>▪ Social exclusion</li> <li>▪ Culture and mental illness</li> <li>▪ Social security</li> <li>▪ Community based rehabilitation.</li> </ul>             | <ul style="list-style-type: none"> <li>▪ Sustainable</li> <li>▪ Socio cultural</li> <li>▪ Rehabilitation</li> </ul>               |

## **2.4.2 Conceptual framework**

A thorough study of conceptual frameworks was done for selection of the conceptual theoretical framework for the thesis. A comparative analysis (44) studied the strengths and weakness of following frameworks for caregiving burden: Family caregiving burden framework by Pallet (1990)(45), Expressed Emotion framework, family stress coping framework and family resiliency model. Expressed emotion framework by Brown, Berley and Wing 1972 classifies families into high or low expressed emotion category and incorporates the effects of psycho education programs in the family. The framework does not look into the contextual influences of burden and hence cannot be adopted for this literature review. Family stress coping framework focuses only on the individual level and not on the level of family whereas the family resiliency model is good for clinical practices only and provides guidelines for a psychiatric nurse on helping families.

Owing to the context of Uttarakhand and the target group of this literature review, the family caregiving burden framework by Pallet 1990 was found to be the most suitable for this review and was adapted accordingly. In order to analyse the family caregiving burden the framework uses the objective and subjective burden as defined by Hoening and Hamilton (1966).

The objective burden is defined by the observable challenges and effects on family due to caregiving for a relative with severe mental illness. The objective burden consists of change in daily routine of household activities, financial problems, constraints on personal and social relations (6). The subjective burden results from the objective burden and is the personal appraisal of the situation by the caregiver. It is the emotional distress experienced due to the illness of the family member and the burden of caring for him/her (6).

In adaptation to the framework, I have kept objective burden and subjective burden together. Social and financial burden are elaborated under objective burden and emotional burden is studied under subjective burden. Objective burden influences subjective burden so in the review they will be discussed together as 'burden'.

Coping strategies of the caregivers are studied as the mediation factors which impact the transition from objective to subjective burden.

Coping is defined as "any response to external life strains that prevent, avoid, or control emotional distress" (2). It describes coping as a way to protect self from ones' emotional life and life strains. Lazarus and

Folkman's stress and coping theory as discussed by Berjot and Gillet in their article "stress and coping with discrimination and stigmatization", had been reviewed to understand the coping strategies of caregivers (46). The coping strategies are studied in two categories: problem focused and emotion based coping strategies.

Problem focused coping aims at tackling a problem directly by changing an aspect of a situation, whereas emotion focused coping refers to strategies regulating emotional responses to the problem (47).

Caregivers' characteristics are studied as predictors of caregiving burden, its relative impact on coping mechanism and access to support. These factors are age, gender, socio economic status, education and religion of the caregivers. These influence the burden or promote certain coping mechanism and define how and what kind of social network they can have and what support they can access. As the study is about caregivers of severe mental disorders and focussed on the role of support in coping with burden, I have not included characteristics of the patient in the framework.

The network and associations around an individual or family lead to a web of social interactions which have been studied as social capital in mental health studies. Social capital means the presence of community linkages and the appraisal of those linkages in terms of trust, reciprocity and mutual help. While elaborating on social support, the social networks have been detailed as an adaption to the framework.

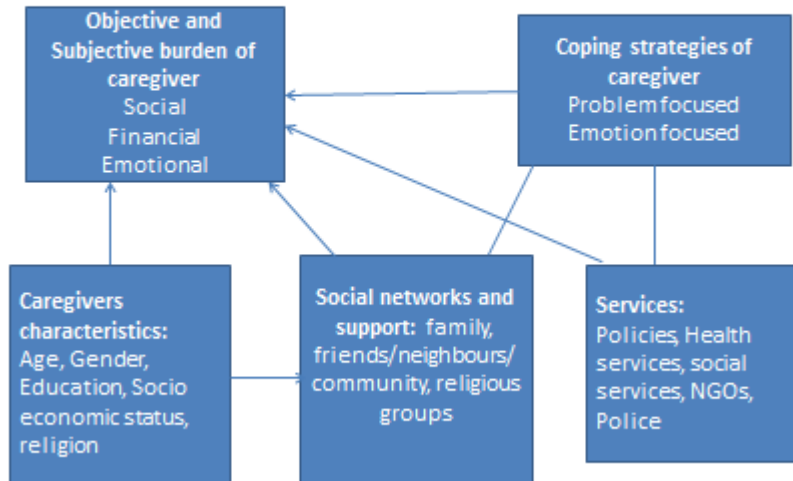
It was important to identify support from other sectors too so the framework is adapted to include section on services. The services: Policies, health and social services have been added to the framework to study their influence on the burden on caregiver.

Cross cutting issues of stigma, gender and poverty impact all the components and will be discussed in narrative. Health and social services are also discussed in the framework as influencing factors that can either increase or reduce the burden and assist in coping with the stress.

The review focuses only on **severe mental disorders** and **family member** as caregiver for the person with severe mental disorders. In the review – the term caregiver/carer specifically means family member who plays the role of caregiver for person with severe mental disorders.

**Figure 2: adapted conceptual framework**

**Framework adapted by author from family caregiving burden framework by Pallet, 1990 (45)**



The findings of the review follow the framework and first identify the burden of caregiving and the coping strategies used by the caregivers. After identification of the burden, the effect and support of socio demographic factors, social networks and health and social services on burden of caring for PWSMDs are analysed in a separate chapter. The findings on interventions for supporting caregivers form the chapter V of the review.

## **Chapter III: Burden and coping mechanisms of the family caregivers of PWSMDs**

*In the findings, I have tried my best to use literatures from Uttarakhand. However, owing to the fact that limited studies have been done on this subject in Uttarakhand, I have used studies from other states of India, as and when required. The studies used are for comparing the situation or building contextual similarities with Uttarakhand for the review.*

This chapter will first elaborate the burden of caregiving experienced by the family caregivers of people with severe mental disorders followed by the coping strategies adopted by the caregivers.

### **3.1 Burden of care giving**

The World Health Organisation 2003 highlighted the impact on quality of life of the family due to the caregiving burden. However due to the difficulty to assess and quantify the extent of burden on families, it is often ignored (48). Caregiving burden consists of objective and subjective burden.

#### **3.1.1 Objective burden**

Objective burden is the burden felt by caring for a mentally ill family member and involves assisting in activities of daily living, providing for daily needs, treatment and adherence, managing the behavioural issues of the person with severe mental disorders and also maintaining personal life work. It has been studied as below as social and financial burden.

##### **3.1.1a Social burden**

***Disruption of domestic routine:*** In the patriarchal society of Uttarakhand, female are burdened with caregiving responsibility along with the already existing household responsibilities (49). A study indicates that burden of caring leads to change in routine of households and caregivers. Caregivers tend to spend most part of the time taking care of the person with mental illness. Presence of a person with mental illness affects the family functioning adversely. For example, wife of a person with Severe Mental Disorders in Uttarakhand said "the children are unable to concentrate on studies because of the problems their father created" (30).

**Family conflicts:** Severe mental disorders impact the reasoning and understanding of the person and the person may doubt and suspect everyone. The PWSMDs often mistrust their caregivers and do not cooperate with them. Caregiver has to compromise his/her time with other family members due to more time spent on caregiving. These may lead to family conflicts and increase the burden on the care giver. The disturbed behaviour, aggressive and violent outbursts of the PWSMD can worsen the situation for caregiver (50). A qualitative research reported that burden also increases in case of the PWSMDs undergoing marital conflicts like divorce and separation in India (30).

**Change in social relationships:** Stigma and misconceptions attached with mental illness, causes difficulties in cordial relationship with family and neighbours. The caregivers felt that the patient was not accepted by the society and faced a sense of isolation from the rest of society. The father of a young man said, *"People stop coming to the house, even close relatives are reluctant to come"* (51). The term, 'mental illness' is associated with negative images in the society. The difficult and aggressive behaviours of people with severe mental disorders make socialisation harder and lead to public stigma and social isolation of their family (52, 53).

### **3.1.1b Financial burden**

With the amount of time related to caregiving which comprises of assisting in activities of daily life, medication and seeking treatment, it becomes stressful for them to maintain balance between their work and caregiving. Studies with caregivers show that most of the time they end up sacrificing their personal and professional growth and quitting work(30). An ngo worker in state of Uttarakhand shared about the plight of a family who sold its fields to meet the financial needs of the treatment of a mentally ill son: *"We had to sell one of our fields when my son became unwell. He needed many expensive tests done, and then medicines, so what else could we do?"* (37).

A study with schizophrenia patients in India shows that care costs for person with schizophrenia and other mental illnesses are 63% for indirect costs (time and loss of work of caregiver) and 29% for direct costs (treatment related cost) (54). This was supported by Dixon and colleague, who reported that free and accessible essential drugs for mental illness led to improvement in quality of life of patient and the caregivers in low and middle income countries. He also brought out the

concern of high out of pocket expenditure involved because of financial and geographical inaccessibility to treatment services (55).

Absence of financial and health care support structure leads to financial stress on the families. Dr. Chavda, senior Psychiatrist in India– stated that “Admission to a good hospital is out of reach for some because of this. It is sad that a patient in an ICU is billed a few lakhs (hundred thousands) but there is no insurance just because it is mental illness” (56). This highlights absence of any insurance structure for people with Mental illness. Poor socio economic status means lesser resources to cope with the caregiving stress and increased emotional distress.

A study (57) equally confirms that even though people knew that traditional healers will not be as effective as medical treatment, they chose to seek help for mentally ill person from the traditional healer because of the financial expenses involved. The families also are burdened of responsibility for the damage of neighbourhood property or criminal conduct of the PWSMDs (58).

### **3.1.2 Subjective/Emotional burden**

Subjective burden is the self- appraisal of the situation by the care givers which originates from the objective burden (6) and is mediated by the coping strategies and resources available. It consists of emotional burden as following:

#### **Worry/fear**

Studies show that sometimes the caregivers give in to the demands of the person with severe mental disorders in fear of being beaten up or mistreated by the person owing to the aggressive and violent behaviours (58). Some parents try to arrange marriage for their adult children with schizophrenia. The parents hope that the spouse would be able to look after their adult child after they die (59).

#### **Guilt**

Societal role expected of men to be the protector and bread earner for family also plays a major role in the emotional burden. When men have to lose their jobs and compromise on the income, it led to sense of poor self-esteem and guilt (30). Women caregivers are often blamed for the mental illness of their children and in few cases the mental illness of the child have also lead to divorce of the parents in India. The absence of knowledge and information about the illness, families often live with the



guilt of having a mentally ill person and ashamed of the weird behaviours of the person in public (60).

## **Depression**

Family caregivers suffer from many negative effects due to the caregiving role like depression, anxiety, grief, and somatic complaints (42). Chaddha (30) highlighted the adverse effects of caregiving role for a family member. High levels of physical and emotional stress were associated with caregiving. One of the caregiver commented "*Sometimes I become so frustrated that I think of either killing him or myself*". Studies report that some of the caregivers developed secondary depression and were seeking treatment. The partners of psychiatric patients' were at a high risk of developing a depressive disorder (34).

Although caregiving has always been linked with negative burden and stress, some studies showed positive aspects of caregiving like fulfilment, spiritual growth, improved relationship between care and care recipient, increased knowledge and development of personal skills. Studies present that closer relationship between care giver and receiver and voluntarily choosing to be the caregivers led to higher satisfaction levels for the carer (61, 62, 63).

## **3.2 Coping strategies of caregivers**

The coping strategies are studied as problem focused coping strategy and emotion focused coping strategy in this review. Based on Indian context and considering the influential factors, religion of caregiver is also discussed in this section.

### **3.2.1 Problem focused coping**

Optimistic attitude and utilization of social supports as family, friends and religious organisations are some aspects of positive coping strategies (64) whereas avoidance, negative thinking and affiliation to drugs and alcohol are considered as negative coping strategies (65).

Greater use of problem solving coping and less use of denial is a predictor of wellbeing in family caregivers (66). The cross sectional study conducted on primary caregivers of patients with chronic Schizophrenia in West India, highlighted fatality and problem solving as the most preferred approaches for coping (67). However, majority of caregivers were reported of not using problem solving strategies like information seeking, positive communication or involving the relative into social activities (68).

As an immediate coping mechanism, families hide their mentally ill family member within their homes in India. This blocks access to medical help and hence enhance the burden on the caregiver (69). Ritu Chatterji, reporter for *Public Radio Internationals - The world*, India reported cases where care givers opted for forceful institutionalisation of the mentally ill women, due to public stigma and inability to care (70). This reduces their objective burden of caring but in turn can lead to feeling of guilt, loss and depression.

The spiritual and religious ways adopted, reflect the attempt of caregiver to find a solution to the condition and are positive emotion focused coping strategy to reduce distress of life. Most caregivers believed in God and thought that He would help them out of this situation. Some of the statements were, *"I do weekly fasting so that he gets well soon"* *"I pray every day and it helps me in difficult times"* (30) It also means seeking help and participating in religious activities. Religious or spiritual coping strategies also had its negative impact leading to neglect of mentally ill person (66). Many times patients are taken to sorcerers and faith healers, and treated with rituals rather than with appropriate medications.

### **3.2.2 Emotion focused coping**

Emotion focused coping strategies are based on emotional response and expressed in form of denial/ avoidance and resignation of the situation. Avoidance and resignation strategies are employed when the caregiver feels that the situation is unchangeable and there is no chance of improvement (71).

Absence of information about mental disorder, no services and support, lead the caregiver to adopt resignation as coping strategy (68).

Cultural beliefs and fatalistic attitude stemming from religious beliefs can also make caregivers accept the suffering as destiny and adopt resignation as coping strategy. Most caregivers felt that one should do one's duty of taking care of their relative with illness.

The caregivers who used denial, avoidance and resignation coping strategies feel more burden (72). Parent caregivers use denial as coping strategy more than spouses. Male spouses can use distraction coping strategies like alcohol or substance abuse as an escape from the burden of caring. This can result in delay in seeking treatment, poor compliance with treatment and neglect of the PWSMDs. The symptoms of PWSMDs if untreated and unmanaged can further increase the burden on caregiver.

## **Chapter IV: Factors influencing caregiving burden of family caregivers of PWSMDs**

This chapter will look into the socio-demographic factors, social networks, health and social services which influence the burden of caring and coping strategies of the caregivers.

### **4.1 Characteristics of the caregiver**

The caregivers characteristics like age, gender, education, socio-economic status and the relationship with the care recipient (spouse, sibling, parent, relative) influences the magnitude of burden felt and the perceived and received social support.

#### **4.1.1 Age of caregivers**

Age is associated with maturity and better ability to cope with any stressful situation. However age related physical competency for a task is often thought to be declining with growing age. This is supported by a cross sectional study in South India which shows that the caregiver burden for mental disorder increases with the age of caregivers and the duration of illness. The younger care givers show lesser emotional stress compared to the older caregivers (50). This can be due to increasing health needs of the caregiver with ageing, the prolonged stress of caring and additional responsibilities of family. However, other factors also play a role in determining the burden on caregivers and age of caregiver in relation with caregiving burden needs to be studied more.

#### **4.1.2 Education of caregivers**

Education plays a positive role in possible employment and access to services. With low education seeking information and knowing about the mental health problems and possible treatments can be a challenging task. The caregiver might feel high burden when he or she does not know what to do, who to ask for help and also manage the financial demands of caring. This is supported by study, which showed that lower the educational level of the caregiver the higher the level of burden of caregiving (50, 73).

### **4.1.3 Socio-economic status**

Person with severe mental disorders are considered to be unable for work and earn money. The treatment expenses, transport costs and related costs increase financial risks. As reported by one NGO worker in Uttarakhand, some families borrow money or take loans to manage treatment expenses of their mentally ill family member (74). Loganathan and Murray (75) reported in their study on employment for Indian men with schizophrenia, that employment and income opportunities was a positive social role aiding in enhanced confidence and self-esteem of the person and their families. A review in India reports that mental disorders lead to decline in the economic status and can lead to financial crisis for affected families (76). Studies have reported the association of poverty to poor health status. Low income is just one aspect of poverty, as social exclusion and denial of equal opportunities also constitute to poverty (77). This inequality and poverty related stress had been linked to risk of development of mental disorders (78).

### **4.1.4 Gender**

In Indian context, the caregiving responsibility lies mostly with the females (49). Culturally men are supposed to be bread earners and women are expected to be caregivers along with their role for running household. The men's work is valued due to economic gains whereas women's caregiving is not valued because it is an unpaid job. The patriarchal society tends to assist men more in the caregiving work as compare to women. Janardanana and colleagues (79) in their study about caregiving role for mentally ill family member stated that women caregivers undergo more stress as compared to the men caregivers. However, another study shows that women who felt satisfied by their role as caregivers tend to have lower levels of anxiety and depression (42). Ampalam and colleagues (50) argued that gender does not have any effect for the caregiving burden for person with mental illness.

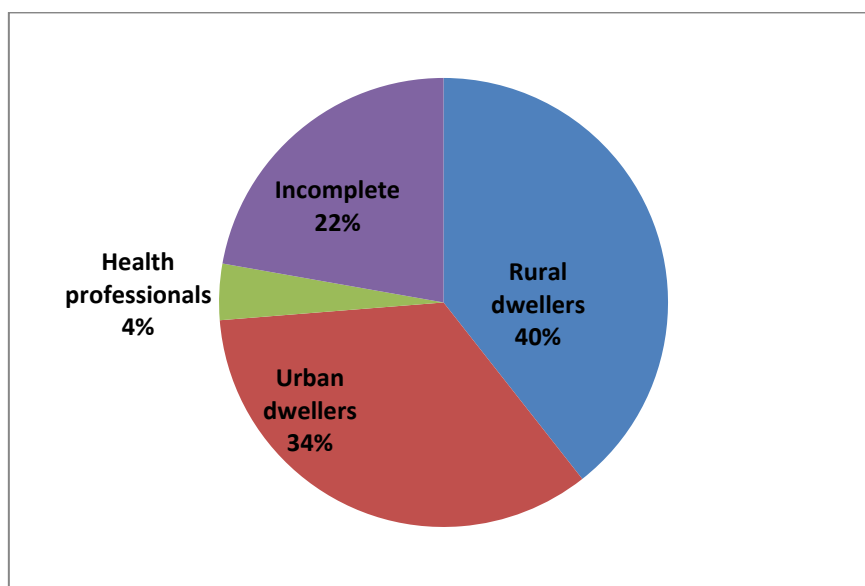
### **4.1.5 Religion**

The debate about the influence of religion on mental health continues between researchers. The positive outcomes of religious involvement, social support and satisfaction help families of persons with severe mental disorders. However few coping strategies in form of some difficult rituals and beliefs about mental illnesses stand as negative impact of religion.

A cross sectional study in India showed varied religious beliefs of caregivers regarding mental illness.

They believed that mental illness in family is due to destiny or ill deeds of previous life. 39.4% people in rural areas, 34.4% in urban areas, and 4% of the health care workers believed mental health problems is bad effects of ghosts/devil/witches. Majority of people believed that daily worshipping and fasting can reduce the severity of mental illness (80).

**Figure 3: Perception about evil/witchcraft as the reason for mental illness (80)**



Different religions see mental illness differently and hence the caregiver feels different reactions and support from religious involvement.

#### **4.2 Social networks and Social support**

Burden is also influenced by the perceived and received social support from social networks. Social support is beneficial for the emotional well-being of an individual (81). Though social support has been stated as the best predictor of caregiving burden in family (82), the family caregivers of person with severe mental disorders struggle to get it (71). People who are socially isolated are at higher risk of diseases and stressful outcomes. Communities see mental disorders as a family issue and not a social concern (83). In this review the social networks studied are family, friends, neighbours/community/religious groups and the bigger network of health and social services.

#### **4.2.1 Family**

Family support indicates the cooperation and support the caregiver gets from the family members and friends. The positive support and cooperation from family members leads to high level of family functioning whereas less support from the family members lead to stress and high burden (71). Studies show joint family system as a good coping mechanism and system for caregiving stress over the nuclear families (84). In Uttarakhand and other parts of India, due to urbanization and migration for employment, the nuclear families are replacing the joint family culture (29). This makes support from family and relatives less accessible. An exploratory research showed mixed reactions of extended family for helping the caregiver. Some families resorted to 'we don't want to know' approach because they didn't want to help. Some had no idea what to do and some families supported the caregiver (85).

#### **4.2.2 Friends/neighbours/community**

Studies show that PWSMDs and their families tend to have smaller social network compared to people without mental disorders. The smaller network impacts on their help seeking behaviour and utilisation of psychiatric services (86). Mathias (74) highlighted the substantial support offered by neighbours to family of PWSMD in Uttar Pradesh, India. The help offered in form of caregiving responsibility at home, financial support and assisting in accessing resources can be interpreted as acceptance and belongingness of the family in the community. One of the caregiver shared: *"At times, I did all the house work or some relatives of ours helped in the household work..... In villages the good thing is that if there is trouble at one person's home, the neighbours will collectively complete their work. People from our village also helped us a lot when she was ill."*

The lack of support for family care givers of person with severe mental disorders are influenced by the attitudes and beliefs of community about mental illness (83). World Health Report 2001 identified stigma for mental illness as one of the reasons for poor support for families of persons with severe mental disorders.

A cross sectional study in Taiwan showed that women tend to find less social support from the communities as compared to males in coping with caregiving burden (87). However Belle as cited by Kawacchi(81),opposed this idea and stated in his study about gender differences and social ties that women maintain emotional relationships, social networks, seek help

from social networks in case of distress and provide social support more than men do.

### **4.2.3 Religious groups/participation**

As Uttarakhand has religion as one of the strong pillars of influence, the participation in the religious activities is key to social life. Satsangs<sup>1</sup> are the traditional practices in India which is a group based approach for spiritual gains and well-being (88). The satsangs have a therapeutic impact as they offer cohesion and caring for the members. Uttarakhand is one of the holy pilgrimage states and holds many satsangs. They can also be called as temporary escape mechanisms as they help in providing opportunities for venting out of stress and grief and share experiences. A participatory research found that developed acceptance of situations, experienced relief from emotional burden and improved wellbeing (89).

Religious involvement is a determinant of better outcomes in physical and mental health as the support from the religious network helps in avoiding loneliness and fight depression (90). However, failure to meet expectations of religious groups or inability to fulfil the norms due to caregiving burden can lead to guilt, stress and social isolation (91). Religion and spirituality are like double edged sword which can cut both ways. The groups can be supportive in absence of stigma and presence of knowledge of the mental illness but on the other hand the religious groups can label and discriminate families of PWSMDs due to misconceptions. The services and support for PWSMDs and the families can be linked to the religious networks as they will be easy and acceptable in society.

## **4.3 Services**

### **4.3.1 Mental health law, policy and program**

**Law:** The national laws and policies are the protectors of human rights of the citizens. Mental disorders are the only illness regulated by legislation (92) however the caregivers of PWSMDs struggle to get the entitlements for their mentally ill family member. The Narcotic Drugs and Psychotropic Substances Act, 1985; Mental Health Act, 1987; and the Persons with Disability Act, 1995 (92) are the three laws related to mental health in

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<sup>1</sup> Satsangs are religious fellowships which mean - living in the path of the truth. The groups are traditional practices in India and do social services in community. They provide venting opportunities and respite for burdened members.

India. The disabilities Act 1995 provides for right to education, employment, social security and financial assistance for people with mental illness but has no specific mention of the caregiver (11, 92).

**Policy:** India's first mental health policy was launched in October 2014 and keeps the poor mentally ill people in consideration and aims to provide universal access to mental health care (92). As Indian health system is decentralized, the implementation of the mental health policy is independently carried out by the states by the state mental health authority. For implementation, there is a need to expand the district mental health program from the current 123 districts to 648 districts in 30 States and Union territories.

Preventive and promotive health activities as per the mental health policy (92)

- *School mental health services on life skills education*
- *Counselling services through trained teachers and counsellors in colleges*
- *Stress management at work place in formal and informal sectors.*
- *Suicide prevention services through awareness programs using Information, Education and Communication tools counselling at district counselling centre and mental health helplines*

However the influence of the policy on caregivers cannot be analysed now but the scarce mental health resources in Uttarakhand and absence of a central governing body for mental health are some of the challenges for effective implementation(9).

**Program:** State mental health plan of Uttarakhand has a community based service aiming at accessible mental health care for populations. It has components of training primary health care personnel, setting up psychiatric services in peripheral areas and promoting awareness about mental health (11).

Jain and Jadhav (93) highlight the implementation failure of the program because of differential understanding by implementers and no involvement of community in North India. The narrow focus of community based mental health aspect resulted as an outreach activity for distribution psychotropic medicines by psychiatrists in peripheral clinics.

Collaborated with NGOs for promotion of mental health is negligible considering the need for awareness. There is no support available for caregivers besides limited programs for awareness on mental health.



There are no separate counselling services and the already burdened PHC staffs are expected to do that. However, caregiver who lives far off from the PHC or doesn't seek medical help for the mentally ill may never avail these counselling services.

Some day care centres have been started under District Mental Health Program in high performing states - Kerala, Goa and West Bengal. However, the services are still minuscule considering the enormous magnitude of the problem (94). Impact evaluation study of the programme shows shortage of staff, inadequate trainings of health professionals, poor motivation and commitments of nodal officer, absence of a central steering structure, inadequate information, education and communication (IEC) materials and low community involvement. Community involvement and partnership with private sectors was suggested for improvement of the DMHP (94).

#### **4.3.2 Social welfare services**

Uttarakhand social welfare department provides disability pension, travel concessions, educational scholarships and incentives for marriage of people with disability (*see annex 3*). Disability due to mental illness is also included under the disability act 1995 (95). It can be said that any financial assistance and concession for PWSMDs is also helpful for the caregiver. However the challenge lies in people being unaware of these entitlements and the difficult processes involved for accessing them. The PWD Act, 1995 emphasises on disability of 40 % and above for obtaining disability certificate for social welfare entitlements by the Government. However, review article by Math and Nirmala (96), criticises the difficult process and ethical issues in the process for getting disability certificate. The subsequent use of the certificate to avail entitled services hampers with confidentiality issue, especially in case of stigmatised mental disorders (97). The difficult process increases financial, social and emotional burden of the caregiver. There are no community based residential facilities for people with mental disorders in Uttarakhand (11).

#### **4.3.3 Health settings and challenges**

##### **Availability**

Uttarakhand has shortage of adequate resources in terms of health facilities, human resources, funding and governance. There are only 7 psychiatrists available for 10.83 million population in Uttarakhand, which

is about 0.08/100,000 population and too low compared to the WHO standard of 1 psychiatrist per 100,000 population (11). All of the 7 psychiatrists work in the state capital and only 2 out of those 7 work in public sector. The private sector provides expensive services and is far from reach of rural communities. As per WHO mental health workforce gap programme, there are only 4.78 nurses per 100,000 population and 2.87 psychosocial care providers per 100,000 population in Uttarakhand. This shows a shortage of nurses mental health professionals in (11). The state mental health institute is the managed by only two psychiatrists (one full time and one visiting consultant) and caters to population of the whole state. The state has an essential drug list including psychotropic medicines but the diagnosis and distribution is questionable owing to absence of mental health workers – adequately trained primary health centre clinical team and volunteers. Government estimates in 2012 which show 10% of primary health centres without doctors (98). The PHC staff is overburdened and mental health care is seen as an additional role. There is shortage of higher centres for mental illness and the psychiatric wards in the hospitals are also poorly managed or used for some other illnesses (99).

### **Accessibility**

The scarce mental health services of Uttarakhand have severe accessibility challenges for caregivers and increase their financial, social and emotional burden. As mentioned earlier the only 7 psychiatrist of state operate in one city which makes geographical accessibility as a burden. Distance from mental health services and the transport expenses and challenges lead to discontinuation of medication (30).

However, the schemes have difficulties in terms of access(100) which is supported by P L Porkodi, (director, The Banyan) who said-*"However, the process of procuring ID cards to judge the extent of mental illness as a disability is a problem. Even if people do manage it, the money does not reach them. Officials tell us that if a GO is released stating that the need of this group is significant, then the pension released may become a reality"*.

### **Affordability**

The high fees charged by the private sectors often lead in decision of discontinuing treatment (78). Absence of financial aid and insurance for mental disorders also adds to the financial burden of caregiving. This is confirmed by studies which stated that financial constraints do not allow the care giver to get services for the ill relative (70, 72, 79). There is no

health insurance for mental illness and the out of pocket expenditure for treatment, if available, is high (11).

### **Acceptability**

Person with mental illness and family and also the health provider for mental illness is stigmatised due to societal perception of mental health. This hampers not just access to mental health care but also limits the provision for physical health needs of the person (101). Sometimes the medical personnel also show discriminatory attitude towards PWSMDs and pay less attention. The unfriendly and non-receptive attitude also influences the social burden on the caregiver (101, 102). The belief that mental illness is incurable or self-inflicted can also be damaging, leading to patients not being referred for appropriate mental health care (102). The unequal, discriminatory treatment and no confidentiality of the person with severe mental disorders is violation of human rights of the person (103). This, in turn, leads to stress for the caregiver as in absence of support and treatment, the behaviour of the PWSMDs can become difficult and unmanageable.

#### **4.3.4 Non- Government Organisations**

North India lacks adequate and accessible support from the private sector and NGOs working in rural areas. Few NGOs in smaller hamlets in the state however, their contribution is negligible compared to the need (37). Raphel and Haldwani institute run half way homes for homeless destitute who suffer from mental disorders, but are unable to accommodate all due to funding and infrastructure constraints. However, other states have NGOs working for mental health awareness and counselling support for the families of PWSMDs.

Some NGOs promote economic support to people affected by mental illness. They do so by providing financial assistance, providing cattle for business and providing vocational rehabilitation which will help in reducing economic burden (104). Few NGOs have started helplines for information sharing and counselling for people battling anxiety and depression. NGOs fill in the treatment gap and also demonstrate low cost care models for people with mental disorders (105).

### 4.3.5 Police

Police force is considered to be part of legal services whose role is to maintain law and order, but in this review I looked at police as part of the social services. The role and potential impact of police cannot be ignored in the scenario of a mentally ill person.

When police beat a mentally ill person or push for forceful institutionalisation, the caregiver goes through social and emotional burden of sadness, loss and guilt for being unable to control the behaviour of PWSMDs. The caregivers then tend to adapt negative coping strategies like locking up, chaining and beating the PWSMDs (70). However, the report *'Treated Worse than Animals': Abuses against Women and Girls with Psychosocial or Intellectual Disabilities in Institutions in India,* by human rights watch reemphasize the role of police that when police finds a PWSMDs wandering in the streets, they can take them to half way homes and institutions for the safety and care (106). However, the news by Hindustan times (36) also spoke of police men abandoning the mentally ill people in isolated areas, rather than taking them to institutional care.

“Women and girls with disabilities are dumped in institutions by their family members or police in part because the government is failing to provide appropriate support and services,”: Kriti Sharma, researcher at Human Rights Watch (106).

As in my experience the complaints by neighbours to police about violent or disturbing behaviour of a mentally ill person, puts the caregiver at stress. The stress of warnings from police and the continuous complaints of the neighbours lead to anxiety, depression and negative coping strategies by the caregivers

## **Chapter V: Evidence based practices in other states and countries**

The identified best practices were chosen in line with the challenges for the support needs for the caregivers. The socio cultural context, low resource situation of Uttarakhand and the feasibility, cost effectiveness and sustainability of the interventions were considered while selecting the interventions. The interventions were also analysed based on the impact they can have in supporting the caregivers by addressing stigma and information gap.

### **5.1 Interventions in other states in India**

**The Home Care Advisor project (HCA)** by Sangath, in Goa funded by Rotary club of Crosby UK, received the Alzheimer Disease International prize for the best psychosocial intervention in 2010, by Foundation Mederic Alzhiemer (107). The project identifies volunteers from community and trains them as home care advisors, to assist families in caring for the patient, provide information and counselling. Training of volunteers from the community makes the intervention acceptable and sustainable. This intervention also promotes formulation of support groups for caregivers and referrals. This program works in collaboration with psychiatrists from both public and private sector. The collaboration helps in training of volunteers and builds an effective referral system. The availability of psychiatrist and psychiatrist nurses made the implementation easier for this program.

This is a cost effective support intervention nourishing on community involvement to address the challenges of low information and inadequate health resources. It is tailored to the needs of the individual and the family and is flexible in its implementation. However the program focused only on caregivers of old people with dementia and not severe mental disorders.

**Janamanas programme:** This is an initiative by Anjali Mental health Rights Organisation in West Bengal. It aims at deinstitutionalising health services, make them affordable, accessible and free of stigma and works with women as main beneficiary (108). The program trains poor women from the marginalised group in communities for running a mental health kiosk in their localities. The counselling based program relies on training of women from communities using a curriculum specifically designed based on the needs of the community. Though the trainings are very

basic but some level of education is required for this kind of work which may be challenge for areas with poor literacy rates. Governance Knowledge Centre, GOI, identified Janamanas program as a best practise for efforts to integrate mental health care into public health care system (109). The use of people from the communities and building them as change agents provides better understanding and access in the communities. The components of the program are information, awareness, counselling and referrals through kiosks and advocacy and assistance in municipal and legal aids and services for people with psychosocial disabilities. However, funding for the programme remains a challenge, as the organisation relies on funding from DFID and Global fund for women. This hampers up scaling of the program in other areas. The primary focus is information and counselling for common mental disorders, so case with severe mental disorder cases come up as a challenge for the kiosks.

## **5.2 Support interventions in other countries**

Family intervention strategies like psycho-education and care giver support groups have proved to be beneficial in schizophrenia patients care (65,67). Support groups are feasible in facility based setting where carers can meet and share.

***Family Association for Mental health everywhere*** is a Canadian organisation, which, uses a self- help model to support families coping with mental illness of family member and burden caregiving. The organisation provides education, information, referrals and counselling to families through family support workers and telephonic consultations. The organisation values and builds on the expertise and coping skills of the families (110). This intervention aims to build self- esteem skills and confidence of the carer, provides a network for information and respects confidentiality of the person with mental illness. It helps in reducing the emotional distress and burnout of the caregiver. The self-help model however is difficult to manage as it requires proper infrastructure like early identification, diagnosis, treatment, skilled workforce, registration of person with illness and communication services like telephone and internet for families to contact the family support worker. The dependency on funds by donors is however a constant concern for the intervention.

Evidences show that in many countries, family caregivers are actively involved in advocating and formulating policies related to family caregiving. **EUROCARERS** is European organisation with representatives

from 18 organisations from different countries and is influential in lobbying with health policy makers in European Union (111). The organisation provides a voice to family caregivers to raise their concerns and needs. The caregivers are informal caregivers of all kind of illnesses and not specific to mental illness. The **International Alliance of Carers organization (IACO)**, is an alliance providing visibility to the carers and lobbying for support and entitlements of family caregivers (112). It has organizations from United States, Australia, the UK, Sweden and the Netherlands. The Organisation's mission is to promote sharing of good practices and learning. This intervention is an example of empowered caregivers who are able to voice their concerns and demand for their rights.

Involvement of community has been the key factor for successful implementation of a program. **Basic Needs Ghana** (113) and **National Alliance for Mental illness (NAMI)** (114) America have acknowledged the importance of traditional healers (Northern Ghana) and faith leaders (America) and involved them as their target stakeholder groups. Besides other activities of the project for mental health, the interventions sensitize and train traditional/ faith leaders on counselling and referrals to mental health services. This aims at bridging the information and psychosocial support gap for caregivers. The basic needs Ghana intervention focuses on acceptability in community, cost effective use of existing resources, cultural sensitivity and community involvement. The fact that only one religion (Christianity) is prevalent in the work area of the intervention makes it more feasible and easy to implement. Basic needs Ghana had been successful in influencing public health facilities to be more accessible (geographically and financially). The assistance provided to caregivers for income generation activities and building leadership for lobbying for services are some of the remarkable achievements of the program (114).

## **Chapter VI: Discussions, conclusion and recommendations**

### **6.1 Discussion**

Mental disorders are viewed as family issue and not a societal concern in many societies. Caring for PWSMDs is a burdensome work for the family in absence of information, services and support.

#### **Burden of caregiving**

As no quantification was done for the burden, it will not be right to state that, one type of burden is higher than the other. Stigma and inadequate mental health services positively affect the social and financial burden of caregiver.

The financial and geographical access for caregivers is a challenge. The cost associated with treatment is over ridden by the associated costs of travel, administrative procedures, assistance in activities of daily life for PWSMDs and loss of work for the caregiver. High out of pocket expenditure for treatment of SMDs, indicates the burden on caregiver. Choosing to go to a less expensive traditional healer, rather than a medical professional or selling fields to get money for treatment from a specialist are the two ends of the spectrum of financial burden and associated coping. Social inclusion and isolation are major social burden for the caregivers.

The analysis doesn't bring out the preferred coping strategies by the caregivers of Uttarakhand, as both problem focused and emotion focused strategies are adopted by them. However stigma and religious perception of the mental disorders play an influential role in the coping strategies adopted by the caregivers. Limited studies are published on the proportionality of the burden and related coping strategies in Uttarakhand and are a potential area for research.

#### **Socio demographic factors- burden and coping**

The patriarchal society of Uttarakhand emphasises on caregiving role for women . The gender roles and societal norms, of women being caretaker and men – the bread winner for the family make women more vulnerable to burden. The low value assigned to work of caregiving, makes the caregivers invisible in policy, programmes and research about mental health.

Socio economic status and religion influence the caregiving role and felt burden in Uttarakhand. As already known, education influences the possibility for employment, access to information and support, the lower



literacy of women compared to men, can therefore, make the women caregivers more vulnerable to caregiving burden. The strong influence of religion on the beliefs and behaviours about mental disorders, is often negative and increases the severity of burden. Poor awareness and information make caregivers vulnerable to believe in the perceptions of supernatural phenomena. Caregivers, who knew that mental disorders are treatable, suffer because of unavailability of mental health services. Costs associated with caregiving, affect the financial situation of the family and add to the burden (77). This will deplete the family's finances and can often lead to debt and poverty. Though, poor economic status can lead to decision of neglecting or avoiding the care recipients, but it cannot be considered as a detrimental factor for the coping strategy. Literatures have also brought out the efforts put in by caregiver to seek help irrespective of socio economic status. Likewise, religion can also be used as both: problem solving and emotion based coping strategy, depending on other influencing factors for the caregiving burden.

### ***Social networks and support: caregiving burden and coping***

The fall back cushion that people have around them in case of crisis is family, friends, neighbours, community groups as direct contacts and health and social services as indirect contacts.

Support and cooperation from family members is the most important help that an individual can derive. Uttarakhand is undergoing the transition from joint to nuclear families owing to urbanization and employment related migration. Women do not receive adequate support in the additional responsibility of caring for the PWSMDs. Families coming forward to assist or walking away from responsibility of PWSMDs positively influences the burden on caregivers.

The perception of the mental illness, the stigma and the relationship of the carer with the society determines whether the community supports or stigmatise the caregiver of PWSMD. In Uttarakhand, the close knit communities are a positive factor for support, however, stigma and misconception about mental disorders affects the support negatively. The willingness of the society to support, and the sense of belongingness, may be used for building in support for the caregivers.

Religion intercedes with almost every aspect of an individual's life in Uttarakhand. People turn to witchcraft or local faith healers in hope of cure for the mentally ill family member and a respite for themselves. This doesn't mean that religion should be understood as a negative influence in case of mental illness in Uttarakhand. It is positive support in terms of

reducing anxiety, loneliness and feelings of helplessness of the caregiver as evident in form of *Satsangs* (religious- social groups) in Uttarakhand (88). The influence of religious groups in providing opportunity to vent out, providing respite and helping in acceptance, may be an existing resource in the community for support interventions for caregivers. However, government has not considered religion as an influencing factor for planning the mental health program.

Support from the networks and family lead to positive coping strategies like seeking information and treatment either from health facilities or religious healers. On the other hand, no support in caregiving may lead to negative coping strategy like neglect and mistreatment of PWSMDs.

Analysis of the findings show stigma related with mental health to be influencing at all levels in Uttarakhand. It is visible in form of labelling and discrimination by the communities and also self- induced such as guilt and shame. Stigma strains family relationship, social interactions, hinders health seeking and access to care for PWSMDs and their families.

### **Health and social services: Caregiving burden and coping strategies.**

The analysis of the findings brings out the neglect of caregivers in the policies, planning and health system in Uttarakhand. The inadequate mental health resources in Uttarakhand, raises the challenges of accessibility, affordability and acceptability for the caregivers. The stigma and discrimination in community and at some health services regarding mental illness add to the social burden.

There is no disagreement about the fact that, treatment of mental disorders will lead to reduced stress of the caregiver, as it can be the immediate need of the caregiver. However, treatment alone may not address the financial, social and emotional burden of the caregivers. The social services are expected to provide support to the PWSMDs and in turn benefit the family. Though, the schemes available for PWSMDs in Uttarakhand may help the caregivers, the processes are miniscule, difficult and time consuming (100). These bureaucratic procedures increase the caregivers' burden and thus he/she may give up trying for these services for the PWSMDs. Making provision for services and entitlements for PWSMDs may be of no help if, the bureaucratic procedures, geographical accessibility and poor support systems hinder the accessibility to them.

Providing only treatment and no social support to access the treatment, is another way of not providing services. Likewise, providing social services

and no treatment, may lead to incomplete support for the caregiving burden. The failure of the services is directly related to the severity of burden experienced and coping strategy adopted by the caregiver.

Collaboration with NGOs and private sector for addressing challenges of health and social services may help in filling the gaps of information, awareness, availability and accessibility for PWSMDs and caregivers. The IEC campaigns and awareness efforts for reducing stigma in Uttarakhand prove to be just a drop in the sea, as they did not intertwine culture and beliefs of community.

### **Evidence based Best Practices for support interventions for family caregivers:**

Given the factors I have looked at the support interventions which addressed the issues of stigma, poor awareness and focussed on community involvement for the support intervention.

As per my analysis of the evidence based practices, support groups are part of all the programs. The support groups have been found to be effective amongst caregivers of PWSMDs, who were on treatment by a health facility. In Uttarakhand, poor information and awareness, inadequate mental health services, difficult geographical terrain and high stigma may pose challenge in support group formation. The support groups might be possible in urban areas, but no mental health services and poor awareness is still a hurdle. Adaptation of support groups for families of PWSMDs might be feasible for information, awareness and social support for caregivers. The existing self- help groups, groups, NGOs and the religion based groups "satsangs," might be possible options for building support group in Uttarakhand. The support can be in the form of assistance in accessing services and managing financial and social burden.

As lack of information and high stigma has been found to be source of burden for the caregivers, the support interventions nationally and internationally keep it as a central theme to their programmes. The interventions from other states of India like the HCA program and the Janamanas program built on the existing resources in the community to train them as providers of information, referrals and assistants in seeking help regarding mental disorders of a family member. The community involvement and consideration of the needs of the families makes these interventions acceptable, feasible and sustainable in long run.

Though the HCA volunteers and the kiosks of Janamanas programme support the caregivers through information and assistance in legal

matters, they do not specifically address the issue of diagnosis and openness to talk about mental illness. The training requirements for the HCA and kiosks are difficult in the absence of mental health personnel and require partnership with private sectors and NGOs for trainings. The referrals and assistance in seeking legal services is another difficulty in Uttarakhand because of poor mental health resources. In the absence of strategic plan for funding, building mental health resources and partnering with private sector, replication of these interventions might be difficult in the state.

The adequate use of existing resources in community, is the key strategy for the basic needs project of Ghana, which acts as a fill in mechanism to support the otherwise poorly resourced mental health services. They build the traditional healers of community as referral agents and counsellors for families with PWSMDs. The predominant religious and cultural context of Uttarakhand can relate to this strategy but will have to be carefully built in to get the balance between religion and health department. The traditional healers and religious leaders are often the first point of contact in case of mental disorders in Uttarakhand. However, replication of this intervention might face the challenge of building understanding between the religion and medical sciences in context of mental illness. Convincing and training the religious leaders and ensuring that they do not lose their position in community, is indeed challenging but worth trying for approach as it is acceptable, feasible and sustainable for the support intervention. NAMI also followed the same approach however contextually and in terms of available resources, it doesn't apply to Uttarakhand.

FAME, Canada and HCA- Sangath share similar concept for caregiver support. However, the need for proper infrastructure and services to be in place for the intervention by FAME, makes it difficult for adaptation to low resource settings of Uttarakhand. Similarly, the interventions focussed on advocacy for rights, entitlements, care and support for family caregivers as in the EUROCARERS and IACO are good but come with a limitation for Uttarakhand. It is known that the involvement of families in planning interventions, raising their concerns and advocating with policy makers is essential for ensuring support from all levels in the society. However, it might be a later step for Uttarakhand, which has to first focus on raising awareness, building support services and fighting the stigma related to mental disorders.

## **Limitations of the study**

The study followed the adapted framework and has helped in addressing the research question. It has been recognised that the characteristics of the patient also play an important role in identifying burden on the caregiver. This study did not focus on these aspects which is a limitation. Although, it allowed a clear focus on the caregivers' role, further research is required on the association of patient's characteristics and support for the caregiver.

The unavailability of research studies in Uttarakhand and limited literature on support for caregivers, has also been one of the limitations of the study.

Religion plays an important role in Uttarakhand and it was difficult to put it either under problem focused or emotion focused coping strategy. Seeking religious and spiritual help is an attempt to solve a problem whereas moral obligation to be care giver and blaming destiny is an emotion based coping strategy.

The adapted framework was detailed and helpful, however, the support and the role of services could have been studied using social ecological model as it is comprehensive and easier to understand. Analysing support for caregivers, through ecological model in terms of layers of interactions in the society could present more insight for planning interventions.

## **6.2 Conclusion**

Families are the primary caregivers for PWSMDs in India, but are seen only as substitute for mental health care. The family caregiver is vulnerable to social, financial and emotional burden. Without adequate support, the burden can lead to possible mental health problems in caregivers. Societal norms, family structure and gender roles affirm the caregiving role to women in Uttarakhand. The caregivers of PWSMDs are the neglected group in the health systems, programmes and policies. Poor socio economic status, stigma, discrimination, poor awareness and inadequate mental health services, are positively associated with the burden of caregiving. Religion plays a pivotal role in perception and treatment related to mental disorders in Uttarakhand. Provision of treatment alone is not the solution, but also building social services is significant for supporting caregivers. Support interventions should be

socio culturally relevant, feasible, able to address stigma, tailored to the needs of the caregiver and involve all layers of the community.

### **6.3 Recommendations**

Following recommendations emerge after analysis of the findings:

#### **Uttarakhand health and family welfare society, Government of Uttarakhand**

1. Promotion of mental health through multi-sectorial collaboration (Directorate of education, ministry of social welfare, private sectors, media and NGOs) to address stigma and build awareness.
  - Media for public awareness about mental health, mental disorders, mental health services and rights and entitlements of people with mental disorders.
  - Community education programs about mental health services, social security schemes and rights of PWMI for CBOs, SHGs, NGO groups and religious groups.
  - Mental health promotion and information centres at public recreation facilities.
  - Psycho educational workshops by psychiatric social workers at PHC level, district level and at the health facilities for caregivers.
2. Strategic plan for recruitment, deployment and redistribution of health services
  - Public private partnership with private sectors/NGOs for increasing coverage, bridging treatment gap, implementation of mental health plan, research, training and rehabilitation services.
  - Advocacy for redistribution of funds for mental health services.
  - Select and train CBOs/religious leaders as focal referral points and counsellors for caregivers.
3. Build mental health component into health insurance schemes to improve financial access for caregivers.
4. Adapt Basic needs Ghana program by utilising the existing community groups and religious groups for supporting the caregivers. This will ensure acceptability and sustainability through community participation and ownership.

**Directorate of School education, Uttarakhand** (as part of collaboration)

5. Promotion of mental health in education system in collaboration with ministry of health Uttarakhand.
  - Inclusion on Mental health in curriculum for primary and secondary schools for addressing gaps in awareness and information.
  - Inclusion of mental health in curriculums of medical schools, nursing colleges, midwives training centres and paramedical trainings.
  - In service training curriculums on mental health for the medical professionals working in the field.

**Non-Governmental Organisations**

6. Collaboration with public health services for promotion of mental health, prevention of stigma and discrimination and support for caregivers for accessing services.
  - Integration of mental health in the on -going programmes and inclusion of caregivers of PWSMDs as stakeholders in the programmes to build their visibility in communities.
  - Enlisting people with mental disorders and getting their families enrolled with the primary health centre.
  - Facilitation in building a referral system for PWMDs to Public mental health services and private medical personnel based on symptomatic diagnosis of the disorders.
  - Training and counselling of family caregivers on caring for person with mental disorders and on self- care.

**Ministry of Health and welfare, Government of India**

7. Evaluation and revision of the national policies and implementation plans for inclusion of caregivers of People with mental disorders.
8. Simplification of the administrative processes for the policies and schemes in terms of accessibility for caregivers.

**Researchers:**

9. Epidemiological study for prevalence of mental disorders, associated burden and coping mechanisms of caregivers in Uttarakhand and India.
10. Study on role of religion and culture in mental health and utilization of mental health services in Uttarakhand.

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## Annex

### Annex 1: Unemployment Rate for Working Age Population (15)

#### State wise Unemployment Rate for Ages 15-59 (%), 2009-10

| State/UTs        | Male | Female | Aggregate |
|------------------|------|--------|-----------|
| Andhra Pradesh   | 7.5  | 8.4    | 7.8       |
| Assam            | 5.6  | 11.5   | 6.4       |
| Bihar            | 15.4 | 30.1   | 17        |
| Chhattisgarh     | 4    | 2.6    | 3.5       |
| Delhi            | 0.6  | 2.3    | 0.8       |
| Goa              | 20.9 | 45.1   | 28.2      |
| Gujarat          | 8.5  | 12.5   | 9.6       |
| Haryana          | 6.8  | 22.1   | 8.6       |
| Himachal Pradesh | 6.9  | 4.5    | 6.4       |
| Jammu & Kashmir  | 5    | 6.1    | 5.1       |
| Jharkhand        | 22.9 | 41.3   | 27.6      |
| Karnataka        | 2.6  | 3.9    | 3         |
| Kerala           | 7.4  | 21.9   | 11        |
| Madhya Pradesh   | 6.8  | 13.4   | 8.3       |
| Maharashtra      | 4.5  | 8.6    | 5.8       |
| Meghalaya        | 12.3 | 9.7    | 11.3      |
| Odisha           | 7.9  | 16.9   | 9.2       |
| Puducherry       | 7.1  | 47.6   | 16.5      |
| Punjab           | 10.6 | 14.2   | 11.1      |
| Rajasthan        | 11.6 | 35.8   | 18.1      |
| Sikkim           | 4.7  | 9.7    | 6.5       |
| Tamil Nadu       | 4.6  | 8.6    | 5.9       |
| Uttarakhand      | 4.9  | 3.4    | 4.6       |
| Uttar Pradesh    | 7.3  | 19     | 8.2       |
| West Bengal      | 8.1  | 26.3   | 11.4      |
| All India        | 8    | 14.9   | 9.5       |

Source: MoLE(Ministry of Labour and Employment)- Labour Bureau: Report on Employment and Unemployment Survey (2009- 2010); PRS

## Annex 2: Variance in prevalence of psychiatric morbidity in India (23)

Prevalence of psychiatric morbidity in the general population

| Investigator                 | Year | Center      | Location | Population | Prevalence/1000 |
|------------------------------|------|-------------|----------|------------|-----------------|
| Surya[8]                     | 1964 | Pondicherry | U        | 2731       | 9.5             |
| Sethi <i>et al.</i> [9]      | 1967 | Lucknow     | U        | 1733       | 72.7            |
| Dube[10]                     | 1970 | Agra        | M        | 29,468     | 18              |
| Elnager <i>et al.</i> [11]   | 1971 | Hoogly      | R        | 1393       | 27              |
| Sethi <i>et al.</i> [12]     | 1972 | Lucknow     | R        | 2691       | 39.4            |
| Verghese <i>et al.</i> [13]  | 1973 | Vellore     | U        | 1887       | 66.5            |
| Sethi <i>et al.</i> [14]     | 1974 | Lucknow     | R        | 4481       | 67.0            |
| Thacore <i>et al.</i> [15]   | 1975 | Lucknow     | U        | 1977       | 81.6            |
| Nandi <i>et al.</i> [16]     | 1975 | West Bengal | R        | 1060       | 102.8           |
| Nandi <i>et al.</i> [17]     | 1979 | West Bengal | R        | 3718       | 102             |
| Shah <i>et al.</i> [18]      | 1980 | Ahmedabad   | U        | 2712       | 47.2            |
| Mehta <i>et al.</i> [19]     | 1985 | Vellore     | R        | 5941       | 14.5            |
| Sachdeva <i>et al.</i> [20]  | 1986 | Faridkot    | R        | 1989       | 22.12           |
| Premrajan <i>et al.</i> [21] | 1993 | Pondichery  | U        | 1115       | 99.4            |
| Shaji <i>et al.</i> [22]     | 1995 | Erankulam   | R        | 5284       | 14.57           |
| Sharma and Singh[23]         | 2001 | Goa         | M        | 4022       | 60.2            |

## **Annex 3: Uttarakhand, Schemes for Persons with Disabilities by Directorate of Social Welfare (96)**

### **State Disability Pension**

The scheme of state disability pension is known as Viklang Bharan Poshan Anudaan and given to the people with disabilities for their maintenance. This is fusion of state as well as Indira Gandhi National Disability Pension Scheme (IGNDPS). State contribution is Rs. 400/- and IGNDPS contribution is Rs 300/- per month. Total amount of the pension is Rs 700/- per month.

#### ***Eligibility Criteria***

- Above 40 % Disability
- Age group of 18-79 years
- Belong to BPL category or those who don't have any source of income
- Must be resident of Uttarakhand

#### ***Documents required***

- Disability certificate
- Age proof
- BPL card/income proof
- Resident proof

#### ***Procedure for application***

In rural area, applicant can contact Gram Panchayat Vikas Officer/Block Development Officer and submit it at the same place. Form should be attested by Head of the village

In urban area, applicant can contact District Social Welfare Officer to avail the scheme. Form should be attested by Tahsildar/collector.

#### ***Mode of payment***

The amount will be credited into saving bank account or saving account in post office of the applicant.

## **Educational scholarship**

The children with disabilities and also children of disabled parents are entitled to scholarships at the rates given below for the period of 12 months for all standard/class.

- For classes 1 to 5: Rs 50 per month
- For classes 6 to 8: Rs 80 per month
- For classes 9 and 10: Rs 170 per month
- For classes 11 and 12: Rs 85 and 140 per month for day scholar and hostellers respectively.
- For graduation: Rs 125 per month Rs 180 month for day scholar and hostellers respectively.
- For post-graduation: Rs 170 and 240 per month for day scholar and hostellers respectively.
- For professional courses: Rs 170 and 240 per month for day scholar and hostellers respectively.

### ***Eligibility Criteria***

- The monthly income of the parents of the children (children with disability or children of parents with disability) must not exceed Rs 2000/-
- Disability above 40%
- Resident of the state
- Student should have scored passing marks in the previous annual examination

### ***Documents required***

- Disability certificate
- Statement of mark sheet
- Income proof
- Passport size photographs

### ***Procedure for application***

The application form for the scholarship is available at all schools approved by Sarv Siksha Abhiyan and must be filled up and submitted to the school itself. Verification and

sanctioning of the grant will be done by Social Welfare Department.

***Mode of payment***

The amount will be credited to the saving account of the student/applicant.

**Bus concession**

People with a disability are entitled to free travelling in the state transport. This facility is available only in local city buses and Uttarakhand roadways buses. The disabled person and his/her escort are both entitled to this facility.

***Eligibility Criteria***

- Above 40% disability
- Resident of the state
- Documents required
- Disability certificate
- Residence proof

***Procedure for application***

Applicant needs to visit the Social Welfare Office with these documents – Disability certificate and address proof. Officer will issue a Disability Card which will be used as Bus pass.

**Incentive award for marriage between disabled and non- disabled**

The state provides financial assistance for the marriage between disabled and non-disabled. Amount of incentive is Rs 14000 /- in case of female spouse is disabled or both spouses are disabled. But if only male part is disabled then the account is Rs. 11,000/-

***Eligibility Criteria***

- Resident of Uttarakhand at least since last 5 years
- No records of crime and legal punishment
- Age of groom and bride at the time of marriage should be between 21 years to 45 years and 18 years to 45 years respectively.
- Marriage should have been done either through the cultural customs or registered

marriage

- Both of them should not be in the category of tax payer
- Person should not have any living spouse and not be involved in any criminal case or woman exploitation case.

***Documents required***

- Age proof
- Disability certificate,
- Income proof
- Joint bank account no.
- Joint photo of the couple

***Procedure for application***

Applicant needs to contact to Gram Panchayat at village level and can contact District Social welfare Office in concerned district for the application and submission.

***Mode of payment***

A lump- sum money will be given to the couple by the District Social Welfare Department