

**SOCIAL SUPPORT AND QUALITY OF LIFE ACROSS GENDER
AMONG PERSONS WITH PHYSICAL DISABILITIES IN
AIZAWL, MIZORAM**

*Thesis submitted in fulfillment of the requirement for the degree of
Doctor of Philosophy in Social Work*

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CERTIFICATE

This is to certify that the thesis ‘Social Support and Quality Of Life across Gender among Persons with Physical Disabilities in Aizawl, Mizoram’ submitted by Lalhrualtuangi Chhange for the award of Doctor of Philosophy in Social Work is carried out under my guidance and incorporates the students’ bonafide research and this has not been submitted for award of any degree in this or any other University or Institute of learning.

This is being submitted to the Mizoram University for the degree of Doctor of Philosophy in Social Work.

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I, **Lalhruaitluangi Chhangte**, hereby declare that the subject matter of this thesis is the record of work done to me, that the contents of this thesis did not form basis of the award of any previous degree to me or to the best of my knowledge to anybody else, and that the thesis has not been submitted by me for any research degree in any other Universities / Institute.

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List of Abbreviations

AAY	Antyodaya Awaas Yojana
ADIP	Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances Scheme
ALIMCO	Artificial Limbs Manufacturing Corporation
APL	Above Poverty Line
BPL	Below Poverty Line
CBOs	Community Based Organizations
CBR	Community Based Rehabilitation
CPD	Center for Peace and Development
DAS	Differently Abled Society
DDRC	District Disability Rehabilitation Center
DDRS	Deendayal Disabled Rehabilitation Scheme
DPOs	Disabled People’s Organizations
FGDs	Focus Group Discussions
GoI	Government of India
GoM	Government of Mizoram
HRQOL	Health-Related Quality of Life
IGNDPS	Indira Gandhi National Disability Pension Scheme
KIIs	Key Informants Interviews
LC	Local Council
LPS	Laldailova Pachuau & Sons
MHIP	Mizo Hmeichhe Insuihkhawm Pawl
MUP	Mizoram Upa Pawl
MZU	Mizoram University
NGOs	Non-Governmental Organizations
NHFDC	National Handicapped Finance and Development Corporation
NIOH	National Institute for the Orthopedically Handicapped

NPRPD	National Programme for Rehabilitation of Persons with Disabilities
NSAP	National Social Assistance Programme
NLUP	New Land Use Policy
NSSO	National Sampling Survey Organization
PRA	Participatory Rural Appraisal
PwD	Persons with Disability
PwD Act	Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995
PwPD	Persons with Physical Disability
QOL	Quality of Life
SCERT	State Council for Education Research and Training
SIPDA	Schemes for Implementation of Persons with Disabilities Act
SSA	Sarva Shiksha Abhiyan
SWD	Social Welfare Department
TNT	Thutak Nunpuitu Team
UNCRPD	United Conventions on the Rights of Persons with Disabilities
UN	United Nation
WHO	World Health Organization
YMA	Young Mizo Association
ZEP	Zoram Entu Pawl

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CHAPTER I INTRODUCTION

The study explores the Quality of Life and Social Support of Persons with Physical Disabilities (PwPDs). It seeks to profile Persons with Physical Disability, examine their psycho-social challenges, find the Quality of Life across gender, assess their social support and suggest measures for policy making and for social work intervention.

It is identified that “Over the last 20 years, changing social attitudes towards Persons with Disability and their own increasing aspirations have been reflected in every aspect of living arrangements” (Goodall, 1988, p. 173). People with Disabilities are the world’s largest minority, yet they are excluded from most educational, economic and social opportunities. “Persons with Disabilities have to face problems not only because of their handicap but also due to non-addressal of their socio-emotional needs” (Singh, Sharma, Chandra, Nigam & Verma, 2011, p. 20). Barnes and Mercer mentioned that “when perceptions regarding rehabilitation of Persons with Disability are slowly changing and the 1960s’ show a gradual but increasing realization amongst politicians, policy makers and social scientists, across the world that the problem of disability can no longer be considered in purely individualistic medical terms” (as cited in Barnes, 2003, p. 7).

The Disabled People’s Movement during 1970s’ led to the development of disability studies as an academic discipline (Oliver & Barnes, 2010). As mentioned by Barton the emergence of social model of disability led to the understanding of disability as social oppression and this came connected with disability rights, social justice and human rights and therefore disability studies gradually emerged as an important studies in higher education (as cited in Oliver & Barnes, 2010). Though Persons with Disabilities have rights and dignity, they were still seen as *second citizens*. They continued to be the victims of discrimination, stigma and oppressed by

the society (Cobley, 2013). In many cases they were excluded from developmental plans and policies. Yeo and Moore also explained that reliable data on disability was hardly given priority by stakeholders and disabilities studies was also limited (as cited in Klasing, 2007). Therefore, to have a better understanding of the current situation of Persons with Disabilities research based findings are much needed to be carried out for improving the life of Persons with Physical Disabilities.

1.1. Global Perspective on Persons with Disabilities

As far as history is concerned, mention of Persons with Disabilities can be traced back to the medieval period. Records suggest that during this period, people were helping the poor including Persons with Disabilities by giving alms out of religious obligation. The objective behind this charity was the purification of soul for the givers and there was no effort per se for improving the Quality of Life of Persons with Disabilities. In the late 15 century. It was made compulsory for households to provide funds on a weekly basis for the poor or for People with Disability. Though the government took such responsibility for the maintenance of the poor, specific interventions for Persons with Disabilities was still seen as absent. The Elizabethan Poor Law (1601) introduced a more rational system for relief of the poor. The Law divided the poor into three categories, and in this category 'the impotent poor or unemployable poor' such as the 'sick, old, blind, deaf and dumb, orthopedically handicapped, invalid and mentally sick' were placed in alms houses or they were given outdoor relief. However, it was only after 1905 that the condition of People with Disability began to have meaning with the introduction of Poor Law Commission. The commission recommended that mentally retarded and the sick to be treated in hospitals or institutions and public employment services and insurance for them were started (Jha, 2001). With this development, the Medical Model of Disability began to have its deep root in disability where disability is seen as a malfunction in one's body

that has to be treated or corrected. The individual model or medical model lays emphasis on individual impairments and classifications systems (Fawcett, Featherstone, Fook, & Rossiter, 2000). Jha (2001) also note that ‘Disabled Persons (Employment) Act’ was passed in 1944 in England. It made provisions where employers should compulsorily employ Persons with Disabilities.

During the 20th Century, a rights-based approach towards the care and rehabilitation of Persons with Disabilities was introduced as a result of international conventions and agreements. The Universal Declaration of Human Rights in 1948 discusses equal rights for all human being. With this declaration though not mentioned specifically, People with Disability are to have the same rights as others. The United Nations declared 1983-1992 as the ‘Decade of Disabled Persons’ and the International proclamation ‘The Asia Pacific Proclamation on the full Participation and Equality of People with Disabilities in the Asian and Pacific Region’, 1992 was also made. This was followed by the ‘Asia Pacific Decade of Disabled Persons, 1993-2002’. The rights and dignity of Persons with Disabilities began to have recognition with the coming of the Convention on the Rights of Persons with Disabilities¹ in 2006 (Vanramchhuangi, 2014). The Convention recognized ‘the diversity of Persons with Disabilities, the need to promote and protect the human rights of all Persons with Disabilities, including those who require more intensive support’. Thus, the general principles of the Convention on the Rights of Persons with Disabilities were-

- a) Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons.
- b) Non-discrimination.
- c) Full and effective participation and inclusion in society.

¹ The Convention on the Rights of Persons with Disabilities is an international human rights treaty of the United Nations. The text was adopted by the United Nations General Assembly on 13 December 2006, and opened for signature on 30 March 2007. It came into force on 3 May 2008.

- d) Respect for difference and acceptance of Persons with Disabilities as part of human diversity and humanity; Equality of opportunity.
- e) Accessibility.
- f) Equality between men and women.
- g) Respect for the evolving capacities of Children with Disabilities and respect for the right of Children with Disabilities to preserve their identities.

Cobley (2013) states that the 2006 United Nations Convention on the Rights of Persons with Disabilities (CRPD) is a moment for the worldwide disability movement. The rights of Persons with Disabilities around the world were finally recognized in an international agreement. It emphatically states that the participation of Persons with Disabilities should be regarded as a basic human right, rather than as a charitable obligation. Thus the Rights Based discourse in relation to Persons with Disability had just gained center stage.

“The Convention on the Rights of Persons with Disabilities views disability as arising from the interaction between persons with impairments and attitudinal and environmental barriers. This perception of disability according to Oliver appears to be strongly influenced by the social model, which sees disability in terms of the restrictions placed on people with impairments by the way in which society is organized” (as cited in Cobley, 2013). Exclusion of Persons with Disabilities was caused by societal barriers. The societal barriers brought disability to a person; therefore, social barriers must be removed to provide inclusion of Persons with Disabilities. Cobley (2013) thus explained that “the Convention appears to be based, therefore, on a philosophy that implies services need to be designed in a way that helps to dismantle the disabling barriers that restrict participation” (p.442).

At present, around 15 per cent of the world's population, or an estimated 1 billion people, live with disabilities. They constitute the world's largest minority. This figure is increasing through population growth; medical advances and the ageing process. About 15 out of every 100 people in the

world have a disability. Between 2 and 4 people out of every 100 have really severe disabilities (WHO, 2011). “The International Year of Disabled Persons in 1981 encouraged much interest worldwide in disability. UNICEF has estimated that four-fifth of Persons with Disabilities of the world live in developing countries. The overall low levels of development and inadequate health and social welfare services have all contributed to the persistence of poor Quality of Life among the disabled people in these countries” (Hosain, Atkinson & Underwood, 2002, p. 297). The attention of people world-wide is drawn to Persons with Disability as they mark and observe the International Day for Persons with Disability.²

1.2. National Perspective on Persons with Disabilities

The response to disability by the Indian society can also be traced back from the ancient period. Though disability alone was not much expressed, the services given for Persons with Disability can be seen. The Sacred texts of the Hindus, the Gita mentions that leaders of the society have a social responsibility for the welfare of the people and it was believed that to serve the underprivileged is the dharma. Thus, the nature of service was rendered through charity and believed that the ‘souls of the one who gives shine most’. Therefore, the poor, the needy, the aged and People with Disability were assisted in terms of charity. The evolution of Buddhism in India also laid emphasis on charity and much of history tells us that services were available for the relief of deserving persons such as the distressed, the diseased, the blind, the infirm, the orphans and the helpless women. The kings also offered help and assistance to the needy including Persons with Disability. The coming of the Christian missionaries also played an important role towards the recognition of Persons with Disabilities in India. They started opening homes

² Themes for International Day of Persons with Disabilities-
2013-Break Barriers, Open Doors: for an inclusive society and development for all
2014- Sustainable Development: The Promise of Technology
2015- Inclusion matters: access and empowerment for people of all abilities

for the orphan and the destitute including Persons with Disabilities. The results of social reforms in India also played an important role in developing the situation of Persons with Disabilities in India (in Jha, 2001).³

India has laid down several legislations for the welfare of Persons with Disabilities such as the Mental Health Act, 1987, Rehabilitation Council of India Act, 1992, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 and National Policy for Persons with Disabilities (2006) was also framed. Apart from this, there are certain legislations that talks about disability in some of its chapters such as the Juvenile Justice (Care and Protection of Children) Act, 2000. India also ratified the UN Convention on the Rights of Persons with Disabilities in 2007. The PwD Act of 1995⁴ is the key central legislation that provided certain rights in the areas of education, employment and affirmative action, and other privileges in prevention and early detection of disabilities. The PwD Act of 1995 also provided for non-discrimination in access to public places and modes of transportation in ways to make them accessible to people (Menon, Parish, & Rose, 2014).

The Department of Disability Affairs functions under the Ministry of Social Justice and Empowerment. Currently, the Government of India is providing number of schemes and programmes for the welfare of Persons with Disabilities. However, recognition in terms of schemes and legislations is just one step towards reaching the goal for developing the Quality of Life of Persons with Disabilities. The Quality of Life (QoL) of PwDs varies across the group and the marginalized within the group have poorer QoL as compared to those who are not.

India is home to the largest population of Persons with Disability in the world next to China (Klasing, 2007). In India the population of Persons with

³ For a full reading refer Jha (2001)

⁴ For a full reading refer PwD Act, 1995

Disabilities has increased by a fifth (22.4 %) between 2001 and 2011. The number of Persons with Disabilities which was 2.19 crore in 2001, rose in 2011 to 2.68 crore (1.5 crore males and 1.18 crore females). Rural areas have more disabled people than urban areas. In Maharashtra, Andhra Pradesh, Odisha, Jammu and Kashmir and Sikkim, the disabled account for 2.5 per cent of the total population, while Tamil Nadu and Assam are among those where the disabled population is less than 1.75 per cent of the total population. The growth rate of Persons with Disabilities population is more in urban areas and among urban females. The decadal growth in urban areas is 48.2 per cent and 55 per cent among urban females (The Times of India, 2013).

According to the Census Report, GOI, (2011) in India, the Disabled Population by sex and residence as reported are 26,810,557 (2.21%) of which there are 14,986,202 (2.41%) males and 11,824,355 (2.01%) females. Persons with Visual Impairment comprises of 5,032,463 (18.8 %) of which there are 17.6 per cent males and 20.2 per cent females. Persons with Hearing impairment comprises of 5,071,007 (18.9%), 17.9 per cent males and 20.2 per cent females. Persons with Speech impairment comprises of 1,998,535 (7.5%), 7.5 per cent males and 7.4 per cent females. Persons with Locomotor disability comprises of 5,436,604 (20.3%) of which there are 22.5 per cent males and 17.5 per cent females. Persons with Mental retardation comprises of 1,505,624 (5.6%), 5.8 per cent males and 5.4 per cent females. Persons with Mental Illness comprises of 722,826 (2.7 %), 2.8 per cent males, and 2.6 per cent females, Persons with Multiple Disabilities comprises of 2,116,487 (7.9%) of which there are 7.8 per cent males and 8.1 per cent females and any other comprises of 4,927,011 (18.4 %), 18.2 per cent males, and 18.6 per cent females (Census Report, GOI, 2011).

Cobley reports that the Government of India acknowledged that Persons with Disability constitute an inseparable part of India's growing population of marginal, weaker and vulnerable sections of society. It also referred World Bank report which mentioned that People with Disability are the most

excluded in Indian society. They faced social stigma, poverty and limited access to education and employment. Referring to the National Sample Survey, the employment rate for People with Disability was just 37.6 per cent and this rate was around 60 per cent of that for the general working age population. Though India has a progressive disability policy framework, People with Disabilities in India are still subject to multiple disadvantages. Despite the enormous number, Persons with Disability are still invisible in terms of development interventions and research (Cobley, 2013).

1.3 Local Perspective on Persons with Disabilities

1.3.1 The Context of Study

Mizoram is a storehouse of natural beauty with its endless variety of landscape, hilly terrains, meandering streams deep gorges, rich wealth of flora and fauna. Bordered by Bangladesh on the west and Myanmar on the east and south, Mizoram occupies an importance strategic position having a long international boundary of 722 Kms. It is a land of rolling hills, rivers and lakes. As many as 21 major hills ranges or peaks of different heights run through the length and breadth of the state with the highest peak 'Phawngpui (Blue Mountain) towering 2,065 meters above the sea level. The terrain has, perhaps, the most variegated topography among all hilly areas in this part of the country. The hills are extremely rugged and steep and the ranges and leaving some plains scattered (GoM, 2015).

The fabric of social life in the Mizo society has undergone tremendous changes over years. Before the British moved into the hills, for all practical purposes the village and the clan formed units of Mizo society. The Mizo code of ethics or Dharma moved around 'Tlawmngaihna', meaning everyone to be hospitable, kind, unselfish and helpful to others. Tlawmngaihna to Mizo stands for the compelling moral force which finds expression in self-sacrifice for the service of the others. The Mizos have been enchanted to their new-found faith of Christianity with so much dedication and submission that their

entire social life and thought-process been transformed and guided by the Christian Church Organisation and their sense of values has also undergone drastic change. The Mizos are a close-knit society with no class distinction. Ninety percent of them are cultivators and the village exists like a big family (GoM, 2015).

1.3.2 Perceptions regarding PwDs among the Mizos'

A *Person with Disability* is a more accepted one when addressing people having one or more types of disability. However, from earlier days in Mizoram there were different names given for Persons with Disability namely *Piangsual* (A person with physical deformity), *Ramtuilleilo* (A person who is not in a position to carry out work), *Mi Anglo* (A mentally challenged), *Mi a* (A person with mental illness). These terms are often used derogatorily, however with the emerging awareness of the rights and dignity of Persons with Disability more acceptable terms namely *Rualbanlo* (A physically challenged) and *Vohbik* (A special person) are being used in Mizo for addressing Persons with Disability (In Chhangte, 2013).

In Mizo, there are sayings like '*Piangsual nuith san suh, piangsual in tlai luat a neilo*' which means 'one should not make fun of Persons with Disability and it is never too late to have a disability'. In Mizo tales there is a being called *Pheichham*. He had only one leg and used to travel by the side of a river. As legend has it, anyone who saw him should hold him tight and when they did that *Pheichham* will say "Make a wish and I will give it to you" and he will grant whatever they wished for. So till today whenever a person received something 'good,' people would regard that person as lucky and as if that person had met *Pheichham*. Thus it was evident that even in earlier days a Person with Disability (*Pheichham*) was used as a person who brought blessings to others. However, there is also a saying '*Piangsual leh hmelchhiat a siam that theih loh, nungchang erawh a siam theih*' which means ones' disability and looks cannot be changed but one can change one's behavior (In

Chhangte, 2013). As is evident from these folklore and stories, there have been different ways in the way Persons with Disability are seen in society. The anecdotes suggested that a PwD was symbolizing luck and that taking care of a PwD would reap rewards in terms of blessings for the care giver. Equally held also are the perceptions that a PwD himself or herself is not capable of change (as suggested anecdotically). However what can change is only one's behavior. This latter perception does not take cognizance of the barriers society place for the PwD to effect changes in his/her life.

The GoM (2005) in its Gazette on '*Mizo Hnam Dan*' (*Mizo Customary Law*) mentioned the welfare of Persons with Disabilities. *Highlighted below are some of the Chapters of the Customary Law.*

- i. Chapter 1:19 states that any person with physical weakness should be exempted from doing community work (hnatlang).
- ii. Chapter 1:34 (8) states that any people who are in need should be helped by the community people.
- iii. Chapter 4:82 states the Laws of divorce. It states that if one of the spouses is having mental illness or mental problem his/her spouse should take care of him/her for at least 3 years, if after 3 years the condition cannot be treated then divorce can take place out of necessity.
- iv. Chapter 8:122 states that sexual intercourse with Persons with Disability is an offence and any person who is found doing it will have to pay fines.
- v. Chapter 9:152 states that making fun of Persons with Disability is an offence.

The Government of Mizoram has also passed legislation for the welfare of Persons with Disability in Mizoram. In the exercise of powers conferred under section 73 (1) of The Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Act, 1995 (1 of 1996), the Governor of Mizoram notified 'The Mizoram Persons with Disabilities (Equal

opportunities, Protection of Rights and Full Participation) Rules, 1999'. The 1995 act covers the functions of the central coordination committee as well as the welfare and inclusion of Persons with Disability in terms of employment and non-discrimination by providing barrier free environment etc. In the same way Persons with Disability Rules in Mizoram also covers the welfare of Persons with Disabilities from reservation in Government job, creation for the office of the Commissioner for Persons with Disabilities and Certification Camp etc. Despite many loopholes and drawbacks, Persons with Disabilities Rule is a milestone for People with Disability in Mizoram.

According to Vanramchhuangi (2013), the status of Persons with Disabilities in Mizoram is fair however there is still a long way to go to develop the welfare of PwDs in Mizoram. Sometimes they are ridiculed and stigmatized by the society. Instead of looking for their inclusion and rehabilitation, they are still regarded as helpless and useless. As long as Persons with Disabilities are seen as a 'person who cannot be changed', 'who cannot be a productive citizen', they are likely to be discriminated.

1.3.3 Services and Schemes for PWDs in Mizoram

The Department of Social Welfare, Government of Mizoram takes up the following welfare services and schemes FOR Persons with Disabilities in Mizoram (SWD, GoM, 2014):

- (a) **Fitting of Limbs / Prosthetic Aids:** Fitting of limbs/Prosthetic Aids are provided free of cost in collaboration with Artificial Limb Fitting Centre, Civil Hospital, Aizawl by the State Government to the needy Persons with Disabilities of poor economic background.
- (b) **Aids & Appliances:** The Ministry of Social Justice & Empowerment, GoI provides grant-in-aid under the "Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP) Scheme". Under the Scheme, the State Government has catered Aids and Appliances provided by the ALIMCO to all the Districts of Mizoram which are

then distributed to the needy and poor PwDs to promote their physical, social, psychological rehabilitation at free of cost through the Implementing Agencies, NGOs, etc.

(c) Disability Pension:-

- i. **State Scheme:** The Scheme was introduced in 1996-1997. A disability pension was given to 200 persons who are with disability. Selection of new beneficiary is done among the applicants when there is a vacant seat resulted by death of a beneficiary.
- ii. **NSAP-IGNDPS:** National Social Assistance Programme (NSAP) has been improved and GoM introduced Indira Gandhi National Disability Pension Schemes (IGNDPS) from the year 2009. This scheme covers Persons with Disabilities between 18 to 79 years of age from BPL families.

(d) Economic Rehabilitation (State Scheme): The main objective of this scheme is to provide economic rehabilitation to Persons with Disabilities by providing opportunities to engage them in full or part time employment thereby raising a wage to sustain them or to supplement their family income. One time grant is given to a beneficiary for supporting income generating schemes like piggery, poultry etc. Deserving beneficiaries are selected among the applicants by the Selection Board.

(e) Stipend to Educated Unemployment Allowances (State Scheme): The Scheme was introduced in 1997-98 and educated Persons with Disabilities and who are registered in the Employment Exchange for more than 3 years and who could not be placed in any gainful occupation are given. District Employment Exchange furnishes eligible candidates to the Social Welfare Department, GoM which are then selected by the officials of Social Welfare Department depending on the availability of fund.

- (f) **Handicapped Student Stipend (State Scheme):** Under this Scheme, PwD students who are enrolled in the institutions are given stipend for purchase of books, uniforms etc. Beneficiaries should not be more than three students from one institution.
- (g) **Handicapped Training Centre (State Scheme):** The state Government run tailoring and shoe making training center for both male and female Persons with Disability. Hostel facility is also provided separately for male and female. Sewing machine, treadle machine and cobbler tools are given free of cost to the trainees after completion of 1 (one) year training.
- (h) **National Programme for Rehabilitation of Persons with Disabilities (State Scheme):** The NPRPD is a Central Sector Scheme launched during 1999-2000. The objective is to provide comprehensive rehabilitation services to Persons with Disabilities.
- (i) **Assessment & Certification Camp:** This is carried out jointly by Health Department, SCERT, NIOH and Social Welfare Department at District and Block levels. Camps are being organized to identify Persons with Disabilities and issued disability certificate on the spot.
- (j) **Loan Scheme under National Handicapped Finance & Development Cooperation (NHFDC):** The objectives of the scheme are to promote economic development and self-employment for the benefit of Persons with Disabilities. Under this scheme loan is given to deserving Persons with Disabilities by the Department in collaboration with Mizoram Rural Bank (State Channelizing Agency).
- (k) **District Disability Rehabilitation Centre (DDRC):** For Rehabilitation of Persons with Disabilities at the grassroot level, Ministry of Social Justice and Empowerment with the support of State Government has set up 3 (three) DDRCs in Mizoram and function with a broad objective of identifying, early detection, providing assistive devices and providing orientation training to teachers, Community

members working in the field of disability etc. Persons with Disabilities were identified for appropriate rehabilitation under the scheme and give training to persons working for the welfare of handicapped persons. However, at present these DDRCs are not functioned properly due to limitation of funds.

- (l) **Deendayal Disabled Rehabilitation Scheme (DDRS):** Projects/ Schemes proposed by NGOs are inspected by Social Welfare Department, Government of Mizoram and recommended to the State Level Committee. Projects selected by State Level Committee are forwarded to the Central Government to receive Grant-in-Aid.
- (m) **National Trust:** The object of the National Trust is for the welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability, to promote measures for the care and protection of Persons with Disabilities in the event of death of their parents or guardians etc. The Spastics Society of Mizoram is the State Nodal Agency Centre. Local Level Committee is formed in all the 8 (eight) Districts of Mizoram and Legal Guardianship is the main issue dealt by the Local Level Committee. Local Level Committee is a quasi-judicial body for appointment/ removal and monitoring of Legal Guardians.
- (n) **Office of the State Commissioner for Persons with Disabilities:** Office of the State Commissioner for Persons with Disabilities established in November 2012 with the of objectives to safeguard the rights, coordinate with the concerned Departments, monitoring utilization of funds and facilities made available to Persons with Disabilities. They can be contacted for grievances and other related issues.
- (o) **Schemes for Implementation of Persons with Disabilities (PwDs) Act, 1995:** Ministry of Social Justice & Empowerment releases grant-in-aid to the State government under SIPDA for creation of barrier free environment and providing assistive devices (SWD, GoM, 2014).

(p) **Service providers of/for PwDs registered under Social Welfare Department, GoM:** At present there are 12 (twelve) service providers for PwDs registered under Social Welfare Department, GoM. *List of the service providers are given below-*

- | | | |
|-----|---|--------------------|
| 1. | Zoram Entu Pawl (ZEP) | -Aizawl District |
| 2. | Moriah Blind School/Moriah Association for the Blind | -Aizawl District |
| 3. | Samaritan Association for the Blind/ Special Blind School | -Aizawl District |
| 4. | Gilead Special School/Spastic Society of Mizoram | -Aizawl District |
| 5. | TNT (PangparHuan) | -Aizawl District |
| 6. | Differently Abled Society | -Aizawl District |
| 7. | Presbyterian Hospital, Durtlang | - Aizawl District |
| 8. | Onyx Society of Mizoram | -Lunglei District |
| 9. | Christian Hospital, Serkawn | -Lunglei District |
| 10. | Society for the Mentally Handicapped | -Kolasib District |
| 11. | Hmangaih Society | -Saiha District |
| 12. | Shalom Special School/Shalom Spastic Society | -Serchhip District |

In Mizoram there are 15,160 Persons with Disability. In this, Persons with Visual impairment comprises of 2035, Hearing Impairment comprises of 3354 persons, Speech impairment comprises of 1163 persons and Locomotor disability comprises of 1976 persons, Mental Retardation comprises of 1585 persons, Mental illness comprises of 1050 persons, Multiple disability comprises of 2083 persons. Apart from these categories, any other comprises of 1914 persons. According to the Census report, the total PwD population in Aizawl comprises of 5370 persons (Males=2841, Females=2417). In this, Persons with Visual impairment comprises of 634 (Males=337, Females=297),

Hearing impairment comprises of 1116 persons (Males=624, Females=492), Speech impairment comprises of 353 persons (Males=180, Females=173) and Locomotor disability comprises of 701 persons (Males=424, Females=277), Mental Retardation comprises of 649 persons (Males=337, Females=312), Mental Illness comprises of 533 persons (Males=326, Females=207), Multiple Disability comprises of 768 persons (Males=423, Females=345) and Any other comprises of 616 persons (Males=302, Females=314) (Census Reports, GoI, 2011).

1.4. Definitions and Concepts

The term *Disability* has a variety of connotations that can be interpreted differently (Fairchild, 2002). The Persons with Disability Act (Equal opportunities, Protection of rights and Full participation), 1995, defines Persons with Disability as “*a person suffering from not less than forty percent of any disability certified by a medical authority. Blindness* refers to a condition where a person suffers from any of- Total absence of sight; or Visual acuity not exceeding 6160 or 201200 (Snellen) in the better eye even with correction lenses; or limitation of the field of vision subtending an angle of 20 degree or worse. *Hearing Impairment* as defined in the Act means loss of sixty decibels or more in the better ear in the conventional range of frequencies. *Locomotor Disability* as defined in the Act means disability of bones, joints or muscles leading to substantial restriction of movement or any form of cerebral palsy”.

“A disability may be physical, cognitive, mental, sensory, emotional, and developmental or some combination of these. The term "disability" defined in the International Classification of Impairments, Disabilities and Handicaps developed by WHO, as “*any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being*” (Romney, Brown, Fry, 1994 & Metts, 2000). “The Union of the Physically Impaired defined disability as ‘a

disadvantage or restriction of activity caused by the social environment which takes no, or little, account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Further, American Disabilities Act, 1990 defines disability as a physical or mental impairment that substantially limits one or more of the major life activities” (Mjelde-Mossey, 2006).

“*Social support* has been conceptualized in many different ways as it is a multidimensional concept” (as cited in Huurre, 2000, p. 20). Thompson also explained that “Social support consists of social relationships that provide or can potentially provide material and interpersonal resources that are of value to the recipient, such as counseling, access to information and services, sharing of tasks and responsibilities, and skill acquisition (as cited in Miyahara, 2008, p.14). “Social support is another psychological resource that is associated with better psychological functioning” (Greenglass, Fiksenbaum and Eaton, 2006, p. 18). Social Support is an important construct in reference to QoL since PwDs require enhanced support to enjoy better QoL.

Kahn conceptualized social support and give three functions- “receiving an expression of positive *affect* from another; being *affirmed* through behaviors, perceptions, or expressed views of another; and receiving symbolic or material (i.e., instrumental, informational, and tangible) aid” (as cited in Clingerman, 2004, p. 183).

Some studies have also highlighted the importance of “Social support for individuals with disabilities as an aspect that provides as arena to practice and receive feedback on social skills as well as access to support for dealing with life demands. Social support can be divided into *primary level, secondary level and tertiary levels* on the basis of the intimacy of social relationships. The primary level support structure includes one’s own family and closest friends. The secondary level includes friends, relatives, workmates and neighbors and the tertiary level the authorities and other distant support structure. Social Support may be given by professionals and non-

professionals. The primary and secondary levels include non-professionals and tertiary level professionals” (as cited in Huurre, 2000, p. 21). In the context of Mizoram, the people belong to a very close-knit society, the significance of understanding Primary, Secondary levels of supports gets increased.

Studies also distinguish four types of support such as emotional support (trust, empathy and love), instrumental support (helping behaviors such as giving one’s time and skill), informational support (advice) and appraisal support (evaluative feedback). At the same time measures of support also generally asked persons about their perceptions of the availability or adequacy of resources provided. However, this measure does not quantify the number of supporters or the amount of social contact. It however, attempt to gain individuals confidence that adequate support would be available if needed or to characterize an environment as helpful of cohesive or focus more exclusively on the perceived adequacy of satisfaction with support. According to House and Kahn it is necessary to consider at least two of these three aspects of social relationships within a single study” (as cited in Huurre, 2000, p. 20). *Thus, in order to give Persons with Disabilities opportunities for inclusion in all dimensions of their life, investigating the individuals’ perception on their social world and the type of support they received is needed (Alotaibi, 1997).*

Schippers (2010) cites authors to discuss QoL. “*Quality of Life* as a multidimensional and influenced by personal and environmental factors and their interaction. It is used in the field of research from the 1980s’ and 1990s”. It further mentioned that “Quality of Life is an integrating concept, which takes into account such as normalization, inclusion and empowerment and it is a holistic concept that includes self-image, lifespan, perception, inter and intra personal variability. The domains also cover all areas from health, finance, community, family, employment and education” (p. 279 & 280). The World Health Organization defines Quality of Life (QoL) as “an individual’s perception of their position in life in the context of the culture and value

systems in which they live and in relation to their goals, expectations, standards, and concerns” (as cited in Chandra & Ozturk, 2005, p. 33). It is a broad and complex concept which incorporates physical health, psychological state, and level of independence, social relationships, personal beliefs, and relationship to salient features of the environment. This definition reflects the view that Quality of Life refers to a subjective evaluation which is embedded in a cultural, social and environmental context. Because this definition of Quality of Life focuses upon respondents' *perceived* Quality of Life, it is not expected to provide a means of measuring in any detailed fashion symptoms, diseases or conditions, but rather the effects of disease and health interventions on Quality of Life. The Centre for Health Promotion at the University has also given its definition as “the degree to which a person enjoys the important possibilities of his or her life” (as cited in Chandra & Ozturk, 2005, p. 33). Brown & Brown also explained that “Quality of Life is an evident based concept, thus provides direction for constructing and evaluating disability related policies and practices and also it has to be determined by People with Disabilities and their social network” (as cited in Schippers, 2010, p. 280).

“Quality of Life is a multidimensional phenomenon composed of core domains influenced by personal characteristics and environmental factors. Zautra & Goodhart emphasized that the important component or domains to this context are physical, psychological, social relation and environmental aspects” (as cited in Deuri, 2012).

WHO (explained that “WHOQoL-100 allows detailed assessment of each individual facet relating to quality of life. In certain instances however, the WHOQoL-100 may be too lengthy for practical use. The WHOQoL BREF Field Trial Version has therefore been developed to provide a short form quality of life assessment that looks at Domain level profiles, using data from the pilot WHOQoL assessment and all available data from the Field Trial Version of the WHOQoL-100. The WHOQoL-BREF contains a total of 26 questions. To provide a broad and comprehensive assessment, one item from

each of the 24 facets contained in the WHOQoL-100 has been included. In addition, two items from the Overall quality of Life and General Health facet have been included. WHOQoL BREF version comprises of four domains such as physical health, psychological health, social relationships, and environment". All items are rated on a five point scale. The details of the four domain facets incorporate within domains are as follows: (WHO, 2004):

1. Physical health
 - 1) Activities of daily living
 - 2) Dependence on medicinal substances and medical aids
 - 3) Energy and fatigue
 - 4) Mobility
 - 5) Pain and discomfort
 - 6) Sleep and rest
 - 7) Work Capacity
2. Psychological health
 - 1) Bodily image and appearance
 - 2) Negative feelings
 - 3) Positive feelings
 - 4) Self-esteem
 - 5) Spirituality / Religion / Personal beliefs
 - 6) Thinking, learning, memory and concentration
3. Social relationships
 - 1) Personal relationships
 - 2) Social support
 - 3) Sexual activity
4. Environment
 - 1) Financial resources
 - 2) Freedom, physical safety and security
 - 3) Health and social care: accessibility and quality
 - 4) Home environment

- 5) Opportunities for acquiring new information and skills
- 6) Participation in and opportunities for recreation / leisure activities
- 7) Physical environment (pollution / noise / traffic / climate)
- 8) Transport

Physical Disability generally refers to “impairment that interferes with an individual’s mobility, co-ordination, and communication, learning or personal adjustment. In other words, Physical disorders frequently interfere with person’s capacity to speak to others, to move about independently, to engage in various activities and to develop certain academic and social skills” (Greenglass, Fiksenbaum, Eaton, 2006, & Mjelde-Mossey, 2006).

The discourse of gender in relation to PwDs is often ignored. Connell explained that “*Gender* is the structure of social relations that centers on the reproductive arena, and the sets of practices (governed by this structure) that bring reproductive distinctions between bodies into social processes” (as cited in Meekosha, 2004). Gendered analysis of disability has been particularly valuable in demonstrating the web of social and biological factors that disable people, not just women. Gender has been widely used within the humanities and social sciences as both a means to categorize differences, and as an analytical concept to explain differences (Meekosha, 2004, p. 6).

1.5 Theoretical Framework

The present study also used certain theoretical framework drawn from certain models and theories in order to link them into the practice of research. The models and theories used are:

i) Social System Theory

Further, in the present study, System Theory has been used as a framework for understanding and designing social work interventions. Pincus and Minahan has given three kinds of systems and this has been used for understanding the systems of Persons with Disabilities such as-

- a) Informal or natural systems (family, friends etc.)
- b) Formal systems (community groups, organizations etc)
- c) Societal systems (institutions, hospitals etc)

The significance of System Theory in studying Persons with Physical Disability is that all parts of the systems are connected and what happens in one part of the system will have an effect on all parts of the system. This gives a clear picture of what actually the system is. In practice, the system study is done in two phases (as cited in Rivers, 1993).

1.6 Operational definitions

1.6.1 Persons with Physical Disability

For this study, *Persons with Physical Disability* include persons over the age of 18 years across gender residing within Aizawl District and having one or more defects in vision, speech, hearing and locomotor disability.

1.6.2 Social Support

Social Support includes Emotional, Financial and Instrumental support by *Primary Supporters* (Family, Close Relatives and Friends), *Secondary Supporters* (CBOs, NGOs and Private agencies) and *Tertiary Supporters* (Government). *Instrumental Support* involves the provision of tangible assistance, in the form of material goods, labor, time, or any direct help. *Emotional Support* involves the provision of empathy, affection, love, trust, encouragement, listening, and cares from members of an individuals' social network. *Financial Support* involves financial aid.

1.6.3 Psycho Social Challenges

There are no determined definitions and clear concepts of the Psycho Social Challenges faced by PwDs. It is solely dependent on the perceived challenges faced by the respondents during qualitative method of data collection (Case Studies, Focus Group Discussion, Participatory Approach and Key Informant Interviews).

1.7 Statement of the Problem

The slow progress in expanding opportunities for disabled people in India results in substantial losses to People with Disabilities themselves. The international year of Persons with Disability was even declared in 1976. However, despite the laws, legislations, programmes and services lay down; People with Disability continue looking for opportunities to deal with their challenges as normal persons in the society. Persons with Disability themselves remain largely outside the policy and implementation framework; they remain at best clients rather than active participants in development (World Bank, 2007). In Mizoram the situation is not much better; there are many Persons with Disabilities who are still waiting for access, opportunities and changes in structure so that there is better inclusiveness. Lack of adequate and satisfactory social support for Persons with Disability would hamper the Quality of Life in terms of emotional, physical and social wellbeing lived by them.

Better inclusiveness and an enabling environment would result in an enhanced Quality of Life for the Persons with Disability. Although it would be important to understand the QoL of PwDs in Mizoram, given the context of Social life and particularly of the physical and geographical terrain in Mizoram, this study focuses on the challenges faced by PwPDs in particular. It is with these objectives that this study explores the levels of Quality of Life and Social Support among the Persons with Physical Disabilities in Mizoram.

1.8 Objectives

1. To profile Persons with Physical Disability (PwPDs) in Mizoram.
2. To assess the Social Support of Persons with Physical Disability at the primary, secondary and tertiary levels.
3. To understand the Quality of Life of Persons with Physical Disability.
4. To examine the psycho-social challenges of Persons with Physical Disability.
5. To suggest measures for policy making and for social work intervention.

1.9 Chapter Scheme

Chapter 1	Introduction
Chapter 2	Review of Literature.
Chapter 3	Methodology.
Chapter 4	Results and Discussion
Chapter 5	Conclusion and Suggestion

CHAPTER II

REVIEW OF LITERATURE

There is copious literature related to disability issues, and the selected literature in this study focus on Quality of Life, Social Support of Persons with Physical Disability, Psycho-social challenges, and Inclusiveness of disability as a whole. Review of literature helped in identifying substantive, theoretical, methodological, conceptual issues and addresses them in the context of the present study.

2.1 Conceptual understanding of Persons with Disabilities

Gilson and Depoy (2000) in their paper cited that Medical approach to disability defines “disability as a permanent biological impediment and positions individuals with disabilities as less able than those who can recover from illness or who are non-disabled” (p. 207 & 208). Social model of disability is socially constructed. This lens helps in understanding the ‘problem’ to be addressed by services and supports. Rather than attempting to change or fix the Person with Disability, a social model of disability sets service goals as removal of social and environmental barriers to full social, physical, career and spiritual participation. The author goes on to say that this view of disability has replaced the historical medical model of disability as a deficit, and has had important implications for social action, political agendas, legislation and overall Quality of Life for individuals with disabilities” (as cited in Gilson & Depoy, 2000, p. 208).

The paper by Oliver (2013) stated that the idea behind the social model of disability stemmed from the Fundamental Principles of Disability Document first published in the mid-1970s. The author further claimed that the social model of disability began to bring a collective disability consciousness. It also highlighted the critics point of view regarding social model of disability where they argued that the social model of disability is

only a limited and partial explanation of what happened to the disabled in this current modern world and it does not give rooms for the impairment and sees disability as a unitary group but when in reality, people with disability have their difference in terms of race, sex, gender etc. The paper also highlighted that with the development of social model approach, some disability charities and organizations felt that their dominance of the people with disability was threatened. But the author further confirmed that the social model of disability is nothing more than helping people with disability to improve their lives (Oliver, 2013).

Aldred & Woodcock (2008) also cited that “from the 1970s onwards the social model has inspired disability studies theorists while remaining marginal within sociology. The authors further explained that Disability studies theorists trace the model’s roots to the 1976 declaration by the Union of Physically Impaired against Segregation that disability is a consequence of social oppression, not a person’s impairment. This radical definition roots the problem in social structures rather than prejudiced or discriminating individuals” (p. 487). From their view point, disability can no longer be seen as only individualistic medical terms; rather disability is seen as a socially constructed (Aldred & Woodcock, 2008).

The paper by Oliver & Barnes (2010) studies the work of Len Barton, a pivotal figure in the development of disability studies. They mentioned that disability movement led to the establishment of disability studies. They also mentioned that the emergence of social model of disability led to the understanding of disability and the disability rights and justice. Further, it is stated that people were not disabled by their functional limitations but by the external arrangements of their surroundings or environment in which they lived in. Len Barton argued that social model of disability could be effectively applied for bringing inclusive education, however, this social model approach was rarely adopted and further argued that broader range of educational, political, social and economic issues were also needed to be considered. The

paper also highlighted that The European Union also sees disability as a socially constructed. The European Union stressed that the environmental barriers in society prevent the full participation of people with disabilities in society and these barriers must be removed. The paper claimed that social model of disability must be adopted at the policy level for further improvement of Persons with Disabilities (Oliver & Barnes, 2010).

Freund (2001) examines the relevance of socio-material space to the social model. The author mentioned that “Since disability is not just simply social construction, social arrangements can be over-emphasized. *It argued that the ‘social model ignores bodily change and decay. This means that, impairments cannot simply be accommodated by social-cultural changes’*” (p. 690). However, the author emphasized that “in a fully accessible society, the main feature would be the ‘universal recognition that all structures have to be built and all activities have to be organized for the widest range of human abilities’” (as cited in Freund, 2001, p. 705). It further examined that “the social model is capable of deconstructing the design of existing material culture, the social organisation of its use and the spatial contexts in which such uses take place” (Freund, 2001, p. 801)

Buckingham (2011) states that the Brahmanic Textual Tradition tended to disinherit those who suffered some form of disability and high Hindu tradition marked out those with impairments as of low ritual value as they are unable to perform the funeral rites of the dead. According to the author this was parallel with Leviticus (Old Testament) chapter 21 verses 16-23 where it states that men with disabilities are denied access to temple and no priest with a physical blemish may approach the altar or officiate in ritual practice (Buckingham, 2011). However this tradition represents only one among a range of social traditions. The article emphasizes the unique experience of disability in India and the role of poverty, gender, caste and community in compounding the marginalization felt by people with disabilities. “Disability is as important as ‘race’ or ‘gender’ as an analytic tool in the historical understanding of

oppression and disempowerment. Moreover, the author sees regaining history and insisting on inclusion of the experience of disability in the writing of Indian history as a critical factor in affirming the right of Indians with disabilities to full social and economic participation. *Finally the paper emphasizes the need for 'disability history' to look beyond colonial and postcolonial welfare paradigms and to investigate disability as an aspect of rights*" (Buckingham, 2011, p. 419).

Lin, Knox, & Barr (2014) explore the experiences of disability for a number of Taiwanese adults with a physical disability. Grounded theory approach was adopted in their study and purposive sampling was used and the respondents' experiences of living a life with a physical disability were gained through in-depth interviews. Participants were invited from two non-governmental welfare organizations for PwDs. *The authors reviewed that "cultural views of disability are important for theorizing disability and that it might not be the same across cultures.* Therefore, understanding the cultural context was important for studying disability. *They reviewed the different interpretations of disability across culture and further noted that in Euro-American countries the causation of disability is usually interpreted as disease or genetic disorder. But for Southeast Asian countries disability might be seen as a punishment for the wrongdoing of a family or its ancestors. People's attitudes towards those born with a disability tend to be negative and stigmatizing.* In Songye of Zaire, not all children born with a disability are marginalized and stigmatized, and the word 'disability' does not exist in their language (as cited in Lin, Knox, & Barr, 2014, p. 976). *The study shows that "having a physical disability was found to impact not only on the difficulties they experienced with their body, but also on the emotional aspects of their lives"* (Lin, Knox, & Barr, 2014, p. 971). The study further mentioned that people with disability experienced two types of social relationships such as hurtful social relationships and the supportive ones. It also explained that for understanding disability, understanding cultural differences is necessary and

from the grounded theory perspectives the experience of disability in one culture may not be the same or applicable in other culture (Lin, Knox, & Barr, 2014).

Meekosha (2011) paper argues that when studying disability we have to think broader. The paper places disability in the global context. In this study, it is argued that war and civil strife, nuclear testing, the growth of the arms trade, the export of pollution to ‘pollution havens’ and the emergence of sweatshops contribute to the causes of disability. The author also argued disability studies are marginalized by the dominating countries over the less dominant countries. It further explained this as disabling colonialism and continued to mention that some disability writers and researchers understandably avoid the issue of the prevention of impairment out of fear to return to the medical model of disability. *It is also stated that the traditional ways of supporting impaired people such as the kinship, family and community systems should also be kept in mind.* She indicated that according to Shakespeare “impairment prevention and disability rights are not incompatible and impairment prevention has a major role in the social relations of disability” (as cited in Meekosha, 2011, p. 679).

The paper by Abang (1988) examines the challenges faced by Persons with Disabilities in Nigeria. *It reports that neglect of treating preventable diseases leave many people to become disabled.* Such preventable diseases that caused disability to a person include measles, cataract, malnutrition and trachoma etc. It also reports that the attitudes towards Persons with Disabilities varies according to their myths and superstition held by various tribes within Nigeria. However, disability was seen by majority of the Nigerians as a curse from God. Even the educated families hide their disabled child from the society out of their fear of stigmatization as many of them see the disabled child to be wicked and people with disability were never married by the non-disabled because they were afraid that it would bring misfortune to the family (Abang, 1988). Persons with Disabilities were also perceived as uneducable,

unattainable and unemployable and they were believed to be beggars. Persons with Disabilities were not allowed to hold higher position and generally not allowed to take part in decision making. There is also a notion that family is expected to care for the disabled. The paper also reports that in Nigeria barrier free environment for Persons with Disabilities was very much neglected. Access to education and medical care was also inadequate (Abang, 1988).

The paper by Beaulaurier is also important for understanding the concept of disability for social workers when working with Persons with Disabilities and its issues. The author reviewed the concept of the two models of disability; the medical model and social model. It also considers the key aspects of American Disabilities Act (ADA). The paper discussed the importance and necessities of social workers in understanding the practice of social work in health settings “to augment their practice capabilities with regard to organizational and community work, negotiating skills and advocacy as the knowledge could help in increasing self determination in their dealing with health systems and professionals. *The paper concludes that it is time to think in terms of strengths rather than pathology, solution seeking rather than problem detecting, competence promotion rather than deficit reduction and collaborative partnership rather than professional expertise*” (as cited in Beaulaurier, 2001, p. 85).

2.2 Quality of Life of Persons with Disabilities

The Quality of Life among individuals with severe physical disabilities has greatly improved during the last two decades, partly as a result of well-planned intervention programmes. However, some individuals with physical disabilities do not cope well in their everyday life, no matter how long they have had the disability (Viemero & Kraus, 1998). Studies related to Quality of Life of Persons with Physically Disabled are reviewed in order to relate different studies across culture for better understanding of the objective and subjective life position of Persons with Physical Disability.

The paper by Schippers (2010) focuses on the nature and application of Quality of Life in disability research and practice and in Disability Studies in Netherlands. In the article the concept of Quality of Life from an international perspective is provided. *It mentioned that "Quality of Life is a social construct that involves community, social and family concepts, including health"* (as cited in Schippers, 2010, p. 278). It stated that the decade on the international focus on disability led to the awareness that people with and without disability wants to live a quality life. Thus the concept was started to be in used for designing programs and support with a strong influence on advocacy. It further mentioned that Quality of Life not only reflects the individual causation but on the ecological perspectives as well. *Thus, the aspects of physical, social, cultural and environment was given importance for determining Quality of Life* (Schippers, 2010).

In a study conducted by Chi (2005) influencing factors on health-related Quality of Life of physically disabled persons was investigated. Data was collected from 96 persons with a physical disability in three cities in Korea. Social support and depression were measured by a Social Support Questionnaire 6 and Rosenberg Self-esteem Scale was used to measure self-esteem. The Health-related Quality of Life (HRQoL) was measured by using Smith Kline Beecham Quality of Life Scale (SBQoL). *The findings of this study show that there were significant differences of HRQoL according to monthly income and economic status and all subjects had a high level of depression and low self-esteem. The study also suggest that nursing intervention and counseling programs which improve self-esteem and increase the size of a social support network are needed to promote HRQoL in physically disabled persons* Chi (2005).

Another study by Chow, Lo & Cummins assessed the subjective wellbeing, and examines the correlation between objective and subjective Quality of Life of children with Physical Disability. In this study self-reported non-disease-specific questionnaire was used and the Quality of Life of 72

young Persons with Physical Disability was contrasted with those who do not have disabilities. The analyses revealed that the Physical Disability group had lower objective Quality of Life score but the two groups were not significantly different in subjective Quality of Life score. Further, no correlation was found between objective and subjective Quality of Life in the Physical Disability group (Chow, Lo & Cummins, 2005).

Similarly, the study done by Viemero & Krause assessed Quality of Life in individuals with physical disabilities through questionnaire and individual interviews of 45 subjects of adults with physical disabilities from both Finland and Sweden. *The quantitative analyses of the study shows that satisfaction with one's life situation is a function of the disabled person's occupation or meaningful occupational activities, social integration and his/her sense of the meaning of life.* Further, the study also noted that the length of time since the onset of the disability was a risk factor for the person's feeling of satisfaction and that the disability per se did not decrease the disabled individual's Quality of Life. The individual's capacity to cope with everyday life was of great importance. The author suggests that occupation or meaningful occupational activities as well as social integration at different stages of life should be taken into account when planning intervention programmes in the future (Viemero & Krause, 1998).

Another paper by Romney, Brown & Fry (1994) discussed the strategies that the authors have recommended for producing improved QoL. It is also systematically reviewed in relation to matters of definition, assessment, applications, and directions for future research and practice. The main thrust of this paper considers policies and practices for improving the Quality of Life of people in general and, especially, of those individuals who are afflicted with a mental or physical disability. *It explained that "social activity would appear to advance both quantity and Quality of Life"* (Romney, Brown & Fry, 1994, p. 240).

Kemp (1999) conducted a study on QoL among persons who are aging with a disability. 110 persons aging with a variety of impairments were the target population. Their range age was between 24-94years. And their average age at onset was 24 years. There were 38 males and 72 females. Their average education was 14.5 years. Both positive and negative dimensions of QoL were studied. *The study shows that “the longer people live with a disability, the more satisfying life becomes”* (p. 162). He also found that “Low QoL can be ‘not having’ what you want or, if it were very negative, it could exist in the form of despair, stress, or depression” (p. 159). It also mentioned that “*for people with disabilities, it seems that life dissatisfaction or negative QoL is somewhat more prevalent”* (p.159). *The result of the study also shows that there is positive significance between Quality of Life and community activities. It suggests that assistive technology should be used to increase these activities to have a positive Quality of Life.* These include increased social support, doing valued activities other ways, or developing new community activities. In addition, this research has found that a range of factors impact on the Quality of Life of a person with a disability, other than the impairment experienced. One factor that emerged strongly was social connectedness. The study also reviewed the study conducted by Flanagan where he found that 85 per cent of people with disabilities in all age groups reported that their QoL was good or excellent (as cited in Kemp, 1999).

A study report conducted by Hosain & Atkinson, Underwood (2002) in Bangladesh also examines the impact of disability on the Quality of Life of disabled people in rural Bangladesh. It uses a multi stage method such as door-to-door survey was used in two villages to collect socioeconomic and demographic information on the villagers and for identification of disabled people. Interview method was used among the caregivers to obtain information on disability and how it affected their life. In total, 162 Persons with Disabilities were identified in the study area. *Overall, the study results show that the Quality of Life of Persons with Disabilities was affected by their*

disability particularly on marriage, education, employment, emotional wellbeing, their personal and social wellbeing. The results show that among the respondents more females than males reported that they cannot marry. However, more males than females delayed their marriage and divorced was higher among female respondents. Majority of the respondents also reported that disability had some negative consequence on their employment and among the employed more than a fourth could not earn as much as did people who were not disabled. Half of the respondents also reported they do not participate normally in community activities such as sports, shopping, ceremonies, functions, and religious festivals. In this, there were more females than males. More than half of Persons with Disabilities were looked at negatively by society. Women with disabilities and girl children suffered more from negative attitudes and this result in critical adverse effects on their psychological and social health. The study suggests a combination of educational, economic and intensive rehabilitative measures to be implemented. Good networking between professionals and parents, behavioral counseling, formation of a self-help group, and comprehensive support to families should also be given priorities for the welfare of Persons with Disabilities (Hosain & Atkinson, Underwood, 2002).

It is evident from the studies that the Quality of Life of Persons with Disabilities is significantly related to the economic status, occupation, and monthly income of Persons with Disabilities. The studies also show that the Quality of Life of Persons with Disabilities was higher when Persons with Disabilities have meaningful social integration and social activity. Some of the studies also indicated that depression and low self-esteem is also significantly related to Quality of Life of Persons with Disabilities. *The studies also suggests that for improving the Quality of Life of Persons with Disabilities meaningful occupation, social integration, increased support network and accessible and available support (institution and non-institution) is significantly necessary.*

2.3. Social Support of Persons with Disabilities

Studies related to social support and Persons with Disabilities are reviewed in order to throw light on the issue of social support of Persons with Disabilities. Kaye and Raghavan (2002) review various studies on the relationship between spirituality and disability. They reviewed that a number of researchers found religion as the primary means of coping mechanisms with stress of illness and disability has an important relationships to psychological and physical recovery from illness among Persons with Disabilities and diseases (as cited in Kaye and Raghavan, 2002). They also reviewed through the studies of Sodestrom and Martinson that spirituality decreased fear of death, decreased discomfort, decreased loneliness, increased emotional adjustment and positive death perspective among seriously ill patients *and also reviewed that various studies indicated that “Persons with Disabilities and illness use various spiritual activities to find purpose and meaning and a sense of hope for the future”* (as cited in Kaye and Raghavan, 2002, p. 238). *They further mentioned that health care providers need to facilitate their patients in this area but in accordance with the individual spiritual needs* (Kaye and Raghavan, 2002).

In a study conducted by LiLi & Moore (1998) a sample of 1,266 U.S. adults with disabilities, relationships were examined between acceptance of disability and demographic characteristics (age, gender, race, education, marital status, and income); disability conditions (disability onset, multiple disabilities, and chronic pain); and other psychosocial factors (self-esteem, emotional support, perceived discrimination, and hostility). Acceptance of disability was measured by a short version of the Acceptance of Disability Scale. *The authors reported that “self-esteem and emotional support from family and friends played important roles in the participants’ adjustment to disability”* (LiLi & Moore, 1998, p. 13). *“Both the younger respondents and the married respondents reported better adjustment to disability. Favorable acceptances of disability were more likely higher among respondents with higher family*

income than those with low income. However, the study results show that gender, race, and education were not significantly correlated with acceptance of disability” (p.18). Furthermore, “perceived social discrimination against people with disabilities had a significant impact on acceptance of disability” (p. 21). “*Social support has also been identified as a significant element of adjustment to disability and as seen in Miller’s study of 100 patients in a community hospital; he found that patients with family support adjusted to their disabilities better than patients without support did.* The authors also noted that social support mediated the relationship between stressful life events and psychological distress. They also mentioned a study of African Americans with disabilities where social support was positively related to adjustment to disability (as cited in LiLi & Moore, 1998, p. 14).

However, a study carried out by Williams & Bowie (1993) identified unmet needs in the care of severely disabled people aged 16-64years. Detailed personal interview and physical assessment of physically disabled adults; personal or telephone interview with carers was employed. *The study results show that “almost 30 percent of the subjects had unmet needs for aids to allow independence in activities of daily living.* The prevalence of unmet need was higher among subjects whose sole regular professional contact was with health services personnel. Only few of the subjects with communication disorders had ever been assessed by a speech therapist. Therefore the study shows that the needs of severely physically disabled adults in the community especially those with progressive disorders are being monitored inadequately by health professionals” (p. 14).

A review of the United Kingdom with reference to influences from Northern Europe and the U.S.A literature done by Goodall (1988) explained that “*by changing the style and nature of existing provision much can be achieved without necessarily incurring additional cost.* It highlighted that choice as to where to live and how to maintain independence without over-protection or the risk of unnecessary hazards is one of the key principles for

those planning services for people with severe physical disabilities. *It further reviewed that in order to make this a reality we must stop thinking in terms of two extreme alternatives- institutional care or ordinary domestic living. The author also reviewed that people vary greatly in the amount and timing of the help they need, and in their desire for social contact.* The research survey undertaken in England and Wales by the Living Options Project was also highlighted by the author and has shown that accommodation and support services offering physically disabled people a measure of choice and personal autonomy in their lifestyles are few and far between and most health and local authorities do not appear to be actively involved in developing options of care” (p. 188). She reviewed the changing social attitudes towards persons with disabilities and their living arrangement options and the implications of social services was also discussed. It mentioned “policy makers sometimes failed to consult the consumer and the organizational inertia” (p. 188). The living options analyzed in this article includes hospital unit, residential care, and communities, collective and sheltered housing and integrated living. It mentioned that we have to keep in mind that the amount of time and help they need differs. (Goodall, 1988).

A study conducted by Winterowd, Street & Boswell (1998) however seeks to shed light on the effects of disability status and perceived social support on levels of depression and anxiety in college students. One hundred and thirty-nine participants completed measures of anxiety, depression, and perceived social support. The study result shows that “regardless of disability status, college students who perceived lower levels of social support (from family and/or friends) had significantly higher levels of depression and anxiety than college students with higher perceived social support (from family and/or friends). *College students with disabilities had significantly higher depression scores than college students without disabilities.* The study also highlighted implications for mental health professionals and suggestions for future research” (p. 53).

Similarly, a study carried out by Doyle, Moffatt & Corlett in the mid-nineties assessed the perceptions of young adults in terms of access to services, lifestyle and future plans. A survey was undertaken among 65 young people with physical disabilities living in inner south east London, an area of deprivation and ethnic diversity. The study revealed that most people had complex disabilities and were wheelchair users, but it did not follow that those with greater need were being supported more by either statutory or voluntary sectors. In fact, people were losing what contact they once had, particularly with social services. *Access to respite and organized social outlets was strictly limited, particularly for people with complex disabilities. Few had received advice about careers or independent living and almost half of those interviews did not know where to go for family planning advice* (Doyle, Moffatt & Corlett, 1994)

McNett (1987) used a causal model based on Lazarus' cognitively oriented theory of psychological stress and coping among functionally disabled population to determine the effects of social support variables, threat appraisal, and coping responses on coping effectiveness. Data from 50 functionally disabled, wheel-chair-bound individuals discharged within 3 years from two rehabilitation facilities were analyzed using path analysis. Social support variables (perceived availability of social support, perceived effectiveness of social support, and personal constraints to the use of social support) were hypothesized to effect coping responses both directly and through the variable of threat appraisal. Coping responses (use of social support, cognitive reappraisal, emotion-focused coping, and problem-focused coping) were hypothesized to directly affect coping effectiveness and to mediate the effect of all other variables. *The findings of the study indicated that "perceived availability of social support, but not the use of social support, was significantly and positively related to coping effectiveness through the mediating variables of problem- and emotion-focused coping. In contrast to the relationship of marital status to coping effectiveness usually found in the*

literature, non-married subjects coped more effectively and perceived less threat” (p. 98).

Social ties can be particularly useful to disabled people, Kutner (1987) in his study investigated social ties, perceived support, received support, and perceived health status in a sample of 332 disabled persons living in a southeastern metropolitan area of the U.S. Major disability groups represented were musculoskeletal, neuromuscular, cardiac, and end-stage renal disease. According to his study “size of kin networks was inversely related to respondents' socioeconomic status. *Disabled women were less likely than disabled men to be married, more likely to be single-parent heads of household, and more likely to be socioeconomically disadvantaged. The study result also shows that perceived support from family was high for all respondents. But perceived health status did not vary with amount of perceived support, but within disability groups, perceived health status tended to vary with amount of received help” (p. 29).*

Similarly, a study done by Singh, Sharma, Chandra, Nigam, & Varma (2011) assessed bio-social characteristics of physically disabled students and the profile of social support in physically disabled students by using interview method, predesigned and pretested Questionnaire. A cross sectional study was carried out in the age group of 15 years and above. The total respondent was 220 students. The study results show that almost thirty per cent of the parents avoid taking their physically disabled children to social gathering and a little more than twenty per cent of the parents unduly interfere in the affairs of their physically disabled children and about fourteen per cent discriminate among their siblings. It was observed that almost eighty per cent of the physically disabled students were getting support from parents, whereas eighty seven per cent in case of siblings and friends and ninety per cent in case of community. *The study result shows that “majority accepted that family economy was affected adversely by their disability and majority of the students were getting support from their parents, siblings, friends and community at large” (p. 20).*

Greenglass, Fiksenbaum, & Eaton (2006) in their study examine the use of proactive coping in the elderly in relation to their depression and their functional ability. Respondents were 224 community-residing older adults attending various community centers that offered programs for seniors. The age of the respondents ranged from 62 to 98 years, with an average age of 75 years. In this study Krause's Functional Disability Scale was used for measuring functional disability. This measure assessed respondents' difficulties with everyday activities such as dressing, washing, shopping, and using the telephone. It also included more strenuous physical activities, such as doing heavy work around the house (shoveling snow, washing walls), stooping, crouching or kneeling, and lifting or carrying something as heavy as 11.3 kg and Proactive Coping subscale of the PCI for measuring coping, BSI for depression and Social Support Behaviors Scale for measuring social support of persons with physical disable. The study result shows that "Social support was positively associated with proactive coping and negatively with depression. Depression was positively associated with functional disability" (p. 15). *It also shows that "age and chronic health conditions predict to higher levels of functional disability" (p.23). "Additional findings also suggest that social support led to lower depression. Empirical research has shown that older adults who are embedded in active social networks tend to enjoy better physical and mental health, including lower incidence of depression, than those who do not maintain strong ties with others"(p.25). It was found that coping is enhanced by more support providers and this, in turn, relates to better physical functioning which means that proactive coping mediated the relationship of social support to functional disability (p. 26).*

The studies conducted by Cobley examine the impact of the ratification of United Convention on the Rights of Persons with Disabilities (UNCRPD). The study was undertaken in three areas of India: New Delhi, Bangalore, and southern Tamil Nadu. In Bangalore, research focused on a group of three urban schemes, aimed at promoting economic participation through formal-

sector employment. These three schemes form the basis for Case Study One. In Tamil Nadu, research focused on a group of three rural schemes, aimed at promoting economic participation through the self-help group mechanism. These three schemes form the basis for Case Study Two. Data were collected through 57 interviews, four focus group discussions, documentary analysis and observation of project activities and meetings. Interviews were semi-structured. Interviewees represented a wide range of stakeholder groups, and included 11 project beneficiaries, 21 project staff, 9 Government representatives, 4 organization representatives, three donor representatives, two relatives, two employers, two mainstream training providers, two Human Rights Commissioners and one bank manager. Focus groups included two composed of beneficiaries only, allowing them to compare their experiences and express their views within a peer group setting. The two beneficiary groups included a total of 11 participants. The other two groups, 12 participants were composed of project staff and organization representatives. A further 27 Persons with Disabilities participated indirectly, through their attendance at one of three self help group meetings that were observed. The findings of the study show that UNCRPD has a positive impact towards disability in India. It further shows that accurate data is important for planning policies and programmes. The findings also show that government initiatives in terms of schemes and programmes have had positive results in improving the life of Persons with Disabilities. *The study indicate that positive results were seen with the results of adoption of self help group, community based organizations and good dialogue between stakeholders, government departments, communities and the Persons with Disabilities as well. It also further stated that media played an important role in changing the attitude where disability is seen as charities and depicted by media as only a human-interest story. This deeply rooted mind of the people was gradually changed with the improvement of media coverage (Cobley, 2013).*

Fisher & Jing (2008) conducted a research through interviews with policy related participants, including discussions with disabled people, and observations of social services and governance processes in Beijing. Interviews, discussions and observations were conducted with people who participate in policy implementation. Research was conducted in 16 organizations and communities, including 13 individual and group interviews, six social service and policy process observations, three seminars, two training workshops and informal discussions with numerous people. Participants included disabled people living in the community, using services or in official positions, family members, carers and other members of the public and non-government and government officials and researchers. A semi-structured interview process was used. Interviews were in English or Chinese, with translation. *The findings of the study shows that responsibility towards Persons with Disabilities was shouldered by primary family support (Fisher & Jing, 2008).* There was less government services available for Persons with Disabilities and the available ones' from the government required fees which all cannot pay. The available services are mostly given by private, small, non-government initiatives and informal government arrangements. *The study also mentioned "the gap in policy, the absence of community support services to substitute family support with personal care needs; people with disability without family have few alternatives except institutional care or homelessness. These people are the most socially excluded because they are also physically excluded from the community"* (p. 180). *The study also mentioned that local schools are not inclusive for children with special needs. The existing special schools were also available for those who could pay. Though social services such as community centers for Persons with Disabilities were carried out, personal and home based care was absent.* The study emphasized the significance of self-advocacy, community members, non-government organizations and local and central government (Fisher & Jing, 2008).

The paper by Shuhan, Rui, Ailin, Liu & Tang (2011) focuses on the timeline of changes that took place since 1978 for the 83 million Persons with Disabilities in China. The authors' indicate the deplorable situations of Persons with Disabilities in earlier China. However from "the early 90s' the situation change from total discrimination to partial inclusion. Later, they state that Charity organizations were replaced by social relief policies and during the late 90s' to early 20s' reforms policies were started Organizations such as the Chinese Disabled Sports Association (1983), Disabled Persons Federation (1988) China Association for the Disabled, China Paralympic Committee, China Sport Association for the Deaf China Paralympic Committee for the Deaf, China Sport Association for the Mentally Disabled, Special Olympics China have been established and also the 1995 People's Republic of China Sport Law 'supporting sport for the elderly and disabled' was initiated. China has set up more than 3000 sport centers for the disabled. National Games for Persons with Disabilities was also held since 1983. New government policies also support fitness programmes such as Nationwide Fitness Plan of China, The Outline of National Fitness Plan' etc (Shuhan, Rui, Ailin, Liu & Tang, 2011). *"The Chinese government carried out its second 'China National Sampling Survey of Disability' in 2006 and obtained data about disability which was used to develop policies and initiatives in regard to the disabled"* (p. 1197). Though China had given benefits and support to people with different disabilities, including medical services, assistive devices, rehabilitation training, educational subsidies, vocational rehabilitation, employment support, poor relief, accessible facilities and information, and living support, as well as recreational services, "the overall availability of services and support to disabled persons in China is inadequate" (p. 1193). It also lacks physical education facilities and professionally trained educators and coaches. Most disabled people have a low income, which prevents them from participating in sport or purchasing sports equipment. Lastly, Persons

with Disabilities in China face challenges in terms of barrier free environment (Shuhan, Rui, Ailin, Liu & Tang, 2011).

The above studies clearly indicate that People with Disability vary greatly in the amount and time of help they need for adjustment to their disability. Similarly, the amount and type of social support they received is highly responsible for their adjustment to disability. Support from family and friends, income, and access to social outlet or social activities is also significantly related to Quality of Life of Persons with Disabilities. However, unmet needs of people with disability obstruct the independent living of Persons with Disabilities in their daily living. The studies also indicate that religion plays an important role as coping mechanisms for Persons with Disabilities.

2.4. Psycho-social challenges of Persons with Disabilities

“If you never start to integrate society then acceptance can never be achieved. It is visibility and exposure that helps break down the barriers of difference” (as cited in Lindsay, 2004, p. 377). Related studies on the Psycho-social challenges of Persons with Disabilities are reviewed within this section.

Lindsay (2004) explores “the policy and legal context within which students with disabilities seek access to public and private education systems in Australia, especially in the State of New South Wales. The approach is multidisciplinary, drawing on approaches in human rights, law in context and social policy. *The paper noted that “there is a clear mismatch between inclusion policy and the form of legal regulation of disability discrimination in education in Australia, and in New South Wales in particular”*. It also argued that this State undermines the protection of the human rights of individuals with disabilities who seek access to so-called ‘mainstream’ education. Then the author concludes the present paper with Carla’s story, which serves “to demonstrate that inclusive ideals have not yet been appropriately incorporated into law or practice in New South Wales” (p. 373).

Beckett (2009) in an article has also considered “what we know and, more importantly, what we do not know about a range of issues relating to the role that education could/should play in challenging disablism. The author has explored the possibilities/openings for future research in this area and suggests the need for a more elaborate understanding of non-disabled children’s attitudes towards disabled people (not just peers with particular impairments), their knowledge/understanding about disability as opposed to impairment, and their knowledge about the reality of life for disabled people within a ‘disabling society’. *A more detailed examination of current teaching practices/school strategies relating to disability awareness was also suggested. The author also notes that the issue of equal access to good quality education, responsive to children’s experiences and needs irrespective of class, race, gender, sexuality or disability, remains high on the research agenda*” (p. 317).

An article by Palley (2009) also examines the concept of disability and that of the least restrictive environment as well as that of the ‘most inclusive setting,’ explains to whom they apply, and also discusses how they have been defined both in statutes and case law, and elaborates on the role of social workers as a result of the law’s reliance on professional judgment in ascertaining client rights. *The author has explained that “an additional obstacle is that different professions might put greater or less emphasis on potential strengths or weaknesses of their clients when making professional assessment of the most appropriate setting in which a person with a disability should receive care or educational services. It suggests that Social workers need to be aware of potential obstacles and work to ensure that their clients’ voices are included in the assessment process*” (p. 51).

Saetermoe, Scattone & Kim (2001) conducted a study among college students drawn from the Departments of Asian American studies etc. The sample size was 319. The respondents participated voluntarily. The study results reveal that “Asian born participants were more likely to stigmatized disabilities overall (except mental illness than US born participants because of

the level of assimilation. *The cultural differences thus may have health care and psychological implications for those who are disabled and for health care providers*” (p. 699).

Menon, Parish, & Rose (2014) studied the state-level variations in outcomes for people with disabilities to provide an explanation for the contrast between the liberal laws on paper and the challenges faced by people with disabilities in practice. They used average monthly per-capita expenditure as an indicator of economic well-being, instrumental-variable Wald estimator. The results indicate that households with members with disabilities have expenditures that are 14 per cent lower compared with households with able members. This effect is most pronounced among families with male adults and children with disabilities, and in states that are relatively poor, relatively more urban, those that experience extremes in annual rainfall and temperature. The study also refers to a study by Thomas “among children with disabilities in India, girls receive less care than boys and are more likely to die as a consequence and girls tend to receive less education than boys” (as cited in Menon, Parish, & Rose, 2014, p. 393). *It further highlighted that “Persons with Disabilities lived in poverty as they have significantly lower employment rates on average, even though the majority of them is capable of working”* (p. 394). The study also mentioned that according to World Bank estimates from Tamil Nadu shows that almost nearly half (45%) of households with people with special needs reported that they need another adult member of their family to care for them and this results them being absent from work. *The study also highlighted that Thomas argued that “poverty is one of the biggest causes and consequences of disability in India.* People with disabilities in India are among the poorest, often are disabled at birth or before school age, are mostly uneducated and are widely unemployed. Furthermore, the authors reviews Cuong and Mont and note that in families where a parent is disabled, non-disabled children tend to have lower primary and secondary school participation rates” (as cited in Menon, Parish, & Rose, 2014, p. 393).

Mehrotra also argued that “women with disabilities in India face double discrimination due to traditional gender roles and expectations” (as cited in Menon, Parish, & Rose, 2014, p. 394). The study also shows that though the Government is providing services for Persons with Disabilities, many of them were unaware of their rights and eligibility and many of the eligible Persons with Disabilities were uncovered. This suggested that the Government should take responsibilities in organizing awareness programmes and greater effort should be taken for targeting the eligible beneficiaries for the programmes laid down for Persons with Disabilities and further suggests that this should be undertaken in consultation with Non-Governmental Organizations. In conclusion, the study mentioned that a way to ameliorate the economic well-being of people with disabilities in India may rest on improving services at the state level (Menon, Parish, & Rose, 2014).

The article by Hästbacka & Nygård (2013) focused on three questions: how were people with disabilities portrayed as a group? What social rights were seen as essential for them? And to what extent were public authorities, the private and third sector or individuals seen as responsible for fulfilling such claims?. The results show that “although some signs of active citizenship could be found in the debate about disability policy in the Finnish parliament, People with Disabilities were largely framed in a way that rests on classical foundations of social citizenship, rather than from an active citizenship perspective” (p. 137). *Persons with Disabilities were still seen as ‘deserving poor’ and the state has shouldered responsibility towards upliftment of People with Disabilities.* This was against the notion of active citizenship, according to which citizens themselves are expected to be active for their own welfare and their security against social risks. *The article also reviewed that “People with Disabilities still have a lower educational level, a lower employment rate, and that there are many obstacles for their employment”* (p. 133). In this regard, the greatest needs for improvement were believed to exist in the vocational education and training system as well as in the higher education

system. It also “emphasized knowledge and experience that NGOs possess in their role as service producers and advocates of the rights for People with Disabilities. Thus the vitality of their involvement (NGOs, the National Council on Disability, local councils) in decision-making process related to disability policy” (p. 133).

The above studies indicate the importance of inclusion as a policy in tune with legal regulation of disability. One of the studies suggests detailed examination of teaching practices in order to bring inclusion among Persons with Disabilities. It is also noteworthy to mention without incurring additional cost positive development for Persons with Disabilities can be achieved. The studies also show that Women with Disability were likely to face double discrimination. It also highlighted that Persons with Disabilities were likely to live in poverty and seen as *deserving poor*. The state government responsibility in improving their services is another factor that was stressed by these studies.

2.5 Gender studies and Persons with Disabilities

The social barriers that constitute disability are too restricted and the focus is almost exclusively on material barriers that exist in the external social world in employment, education, transport, housing, the built environment and so on. But exclusions are also constructed internally, operating along psychological and emotional pathways (Swain, French, Barnes, & Thomas, 2004). Related studies are reviewed to give light in understanding the challenges that Persons with Disabilities across gender face in their life course.

Alison Sheldon discussed Women and Disability. Any consideration of disability and gender brings the attitudes of the society. *It mentioned that Women with Disability need to be strong to face their daily challenges.* However, the author mentioned that in true sense, oppressions against women are generally considered in isolation one from another, thus weakening any meaningful challenge to the system and marginalizing those, women with

disability, who are subject to more than one form of oppression. The author also pointed out various areas in which women with disability are at a unique social disadvantage—sexuality and sexual identity, stereotypical images and oppressive mores relating to child bearing and motherhood and dominant imperatives around physical and social aspects of self-presentation (as cited in Swain, French, Barnes & Thomas, 2004).

Phillips & McNeff (2005) examine the link between low sexual and low body esteem and intimate partner abuse in women with physical disabilities based on findings obtained from an in-depth qualitative study. *The study results indicate that “women with high degrees of physical impairment are more likely to perceive themselves as sexually inadequate and unattractive than women with mild impairment.* These negative perceptions, combined with a strong desire to be partnered, increased women’s vulnerability to getting into and staying in abusive relationships over time. The study theme includes societal devaluation, low sexual and body esteem, preference for non-disabled men, desire to be partnered, and relationship decision-making” (p. 227).

Another study conducted by Duvdevany (2010) compared the relationship between self-esteem and perceived Quality of Life among Jewish Israeli women with and without physical disabilities, and estimated the moderating effects of marital status and age on these relationships. A quasi-experimental design was employed. A total of 134 women aged from 21 to 45 years participated in the study: 70 of them with disabilities and 64 without disabilities (case and control groups, respectively). The study found “significant differences between these groups in terms of marital status, education and employment. A significant moderating effect of marital status on the association between self-esteem and perceived Quality of Life only among Women with Physical Disabilities. *In cases in which the general self-esteem level was the same, the perceived Quality of Life score was higher among married women with physical disabilities than among single women”* (p. 443).

Tower (2003) a consumer, activist, clinician and social work educator stresses the importance of focusing intensively on multiculturalism and cultural competency in social work with reference to cultural identity of people with disabilities. The writer mentioned that the initiation into disability culture is the key for understanding Persons with Disabilities especially for social workers. The article examines disability through the lens of culture by mentioning that disability is form of human variability. *She further mentioned that disability culture has its sub groups not only the disabled alone. The sub groups includes family members, research and policy groups etc. and this makes the culture of disability dynamics.* Though there are at times divisiveness in the culture of disability culture can be an influential group when claiming against their rights and dignity. The writer also focuses on the mutual language people used against Persons with Disabilities and mentioned that practitioner who were too uncomfortable to say the word *disability* are incapable of being at ease with people who have them. She also highlighted that people with disabilities are among the poorest and least educated Americans. *“The rates of poverty and unemployment are higher among women with disabilities than their male counterparts”* (p. 15). However it was also mentioned that “misconception and prejudice against people with disability cannot be easily eliminated as architectural barriers by mentioning that even after four years of the entering of American Disability Act, the unemployment rate of all people with disabilities actually increased by only an average of 4 per cent” (p. 16).

Rumsey & Harcourt (2004) states that *physical disfigurement has psychological impact, Quality of Life and self esteem upon the individual.* “Much of the available research evidence confirms that a visible disfigurement leads to lowered self-confidence and negative self-image across the lifespan” (p. 85). “It leads to social avoidance and withdrawal and this results in smaller network. *The study also shows that family is likely to be the main provider of support*” (p. 88). It also reviewed how society orients towards disability and

chronic illness. They wrote that disability is social construction. Society has worship the perfect or ideal body, bodily perfection is what people across gender tried hard to have (Rumsey & Harcourt, 2004).

Fairchild (2002) also discusses that if women's worth is measured by physical beauty, women with disability are more likely to be unmarried, marry at a later stage or become divorce and also women with chronic physical impairments rate their life satisfaction lower than the non-disabled women. It gives three factors that is responsible for why women with disability are not married i.e. Men's attitude towards disability, societal attitude and transportation barriers. *The author also "mentioned that women with disability faced double discrimination due to their disability and gender"* (p. 13). Working women with disability in the United States earned less income than their female counterparts (p. 22). Heumann mentioned that "Women with Disability continued to rank lowest on most scales that measure progress, specifically in the areas of employment, poverty, and self-esteem" (as cited in Fairchild, 2008, p. 18). It suggests that social workers do need to understand disability rights movement and the isolation and marginalization associated with people with disability (p. 24).

Meekosha (2004) in the draft entry for the fourth coming of sage encyclopedia of disability covered poverty, marriage, education related to poverty. *The author* stressed on the public arena, private and familial arena, and gender patterns to disability in the developing world. She mentioned that "*the disabled people are likely to live in poverty; women are likely to be poorer than men especially in developing countries where women are often heads of the household*" (p. 4).

Vanramchhuangi (2013), a writer and rights activist in Mizoram, in her book states that "the condition of Persons with Disabilities was miserable in earlier Mizo society. They were mocked and ridiculed. This was worse for people with mental illness. Persons with Disabilities were used as clowns by the village chiefs and village elders in times of travel. They were used to

amuse the village chiefs and elders. Till today, Mizo's have the habit of 'bawl' (Joking) with the disabled" (p. 32). However, the position of Persons with Disabilities improved gradually with time. The Christian missionaries contributed a lot in changing the attitudes of the society towards disability. The author also mentioned that most of the families of person with disabilities are over protective towards the disabled member which makes them more vulnerable to society. Awareness towards disability became more and more popular and with the introduction of PwD Rules in Mizoram, awareness on Disability rights improved. The government initiatives for the welfare of Persons with Disabilities also contributed in creating positive attitudes amongst the mass population. The author however mentioned that the implementation of PwD Act is unsatisfactory in the state and that there is still much to be done (Vanramchhuangi, 2013). Though, there are evidences of care and support of PwDs in traditional Mizo society, PwDs had little place in society.

The studies highlighted that poverty is one of the most important contributing factor of the psychosocial challenges of Persons with Disabilities. It also shows that disability is a social construction and the society is worshipping the ideal and perfect body and this has a negative psychological impact among Persons with Disabilities. The studies also highlighted that married Women with Disability perceived higher Quality of Life, but at the same time strong desire to be married increased their vulnerability. The above studies also show that Women with Disability often faced *double discrimination* because of their disability and because of their gender and they are likely to be poorer than their male counterparts. The studies also indicated that disability has sub groups; family members, research and policy groups and the disability culture can be an influential group for the development of Persons with Disabilities as a whole.

The literature reviewed throws light on the importance of the demographic and economic characteristics of Persons with Physical Disability.

The studies assessed the social support and Quality of Life of Persons with disabilities to highlight level of life satisfaction, coping strategies, significance of social support among Persons with Disabilities. The review of local literature also helped in gaining insights on the position of Persons with Disabilities in Mizoram.

CHAPTER III

METHODOLOGY

3.1 Profile of the study area

The present study was conducted within Aizawl City, the capital of Mizoram, in 17 urban localities of Tlangnuam RD Block. Aizawl is one of the 8 Districts of Mizoram. According to 2011 Census, the population of Aizawl District is 4, 040, 54. It is the highest population among the eight Districts of Mizoram. The population density according to 2011 census is 113 persons per square kilometer. The area of Aizawl is 3575.7 square kilometer. It is the second largest district in Mizoram. Aizawl is located at North of the Tropic of Cancer in the Northern part of Mizoram. It is situated on a ridge of 1132 meters (3715 ft) above sea level, with the ‘Tlawng’ river valley to its West and the ‘Tuirial’ river valley to its East. It is also the store house of all important Government Offices, State Assembly house and Civil Secretariat. Aizawl has a mild, subtropical climate due to its location and elevation (GoM, 2015).

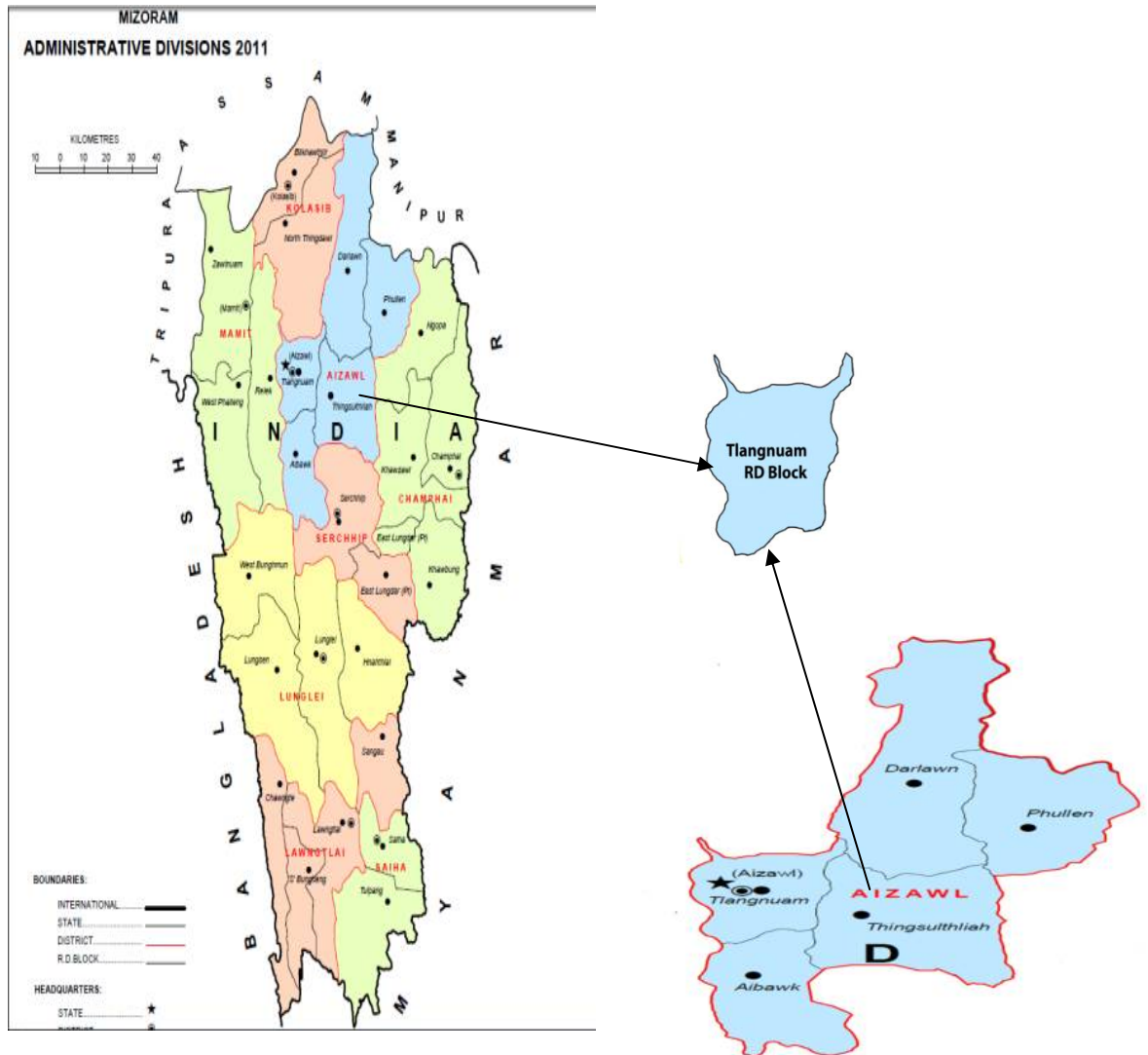
3.2 Research design

The study is cross-sectional in nature and exploratory in design. The study is based on primary data collected through quantitative and qualitative methods by using a semi-structured interview schedule among adult respondents of Persons with Physical Disability who were above 18 years of age. Secondary data from government and non-government sources were also collected. *Persons with Physical Disability in this study included all persons above the age of 18 years with Visual impairment, Hearing impairment, Speech impairment and Locomotor disability residing in Aizawl district.* However, Participatory method such as Services and Opportunities map was used to understand the context of the Persons with Disabilities.

3.3 Sampling

A multi-stage sampling procedure was used for selection of the Veng/Khua/Locality and the respondents. In the first stage, within Aizawl District, the Block i.e. Tlangnuam Block which has the highest population of PwDs was selected⁵. In the second stage, data on the number of PwDs in 70 Veng/Khua/Locality within Tlangnuam Block was collected which included 976 PwDs (Source: CBR Project, NIOH & MZU, 2009-2011). In the next stage, PwDs from each Veng/Khua/Locality were screened for eligibility and filtered in order to meet the operational definition of the study. As such the Veng/Khua/Locality came down to 55 and the population of PwDs came down to 387. *The total sample size was 196 (116 males and 80 females)*. The sample size for the present study is calculated by referring to Krejcie & Morgan (1970). In the fourth stage, the 55 Veng/Khua/Locality were divided into Core and Peripheral Veng/Khua/Locality based on their vicinity (15 km approx.) from the center of Aizawl City i.e Treasury Square, Aizawl. There were 34 Core Veng/Khua/Locality and 21 Veng/Khua/Locality. In the fifth stage, 11 Veng/Khua/Locality from the Core category and 6 Veng/Khua/Locality from the Peripheral category were selected taking into consideration the gender population, distribution and proportion of Persons with Disabilities in each Veng/Khua/Locality. The Veng/Khua/Locality representing the *Core category* were Ramthar Veng, Chanmari West, Electric Veng, Venghnuai, Ramhlun Vengthar, Chhinga Veng, Thakthing, Ramhlun Venglai, Vaivakawn, Tlangnuam and Electric Veng. The Veng/Khua/Locality representing the Peripheral category includes Tuivamit, Tanhril, Sairang, Maubawk, Zemabawk and Sihphir. All in all, there were *109 (72 males and 37 females) respondents representing the Core Veng/Khua/Locality and 87 (44 Males and 43 Females) representing the Peripheral Veng/Khua/Locality as a final sample*. All Persons with Physical Disabilities who fulfilled the age criteria and fall within the selected sample areas and who had given their consent were included in the survey.

Figure 1: Map of the study area



3.4 Tools of Data Collection

A semi-structured interview Schedule was used for obtaining information from Persons with Physical Disability on demographic details and social support. A guide for Focus Group Discussions was prepared to collect information on the perceived challenges and coping mechanisms across gender in respect to disability. Key Informant Interviews were conducted from disability activists, church leaders, community leaders, CBR Project workers and field workers, DPO member and government personnel to obtain information on services and programmes as well as on advocacy issues. Seven Case vignettes were compiled to document the Quality of Life and psycho social challenges of men and women with Physical Disabilities. PRA technique of Services and Opportunities map was also administered. The WHOQoL BREF tool was used to measure the Quality of Life of Persons with Physical Disabilities. The translation process followed protocols established by WHO. The process of translation took approximately two months was taken to co-opt experts in the field for translation work. The following members were forward translators and back- translators of WHOQoL (BREF) tools:

i) *Forward Translators (English to Mizo)*

Miss Ramdinmawii, PhD Research Scholar, English Department, Mizoram University, Mr. David Lalremruata, Lecturer, Government KM Higher Secondary School, Mr. James Lalthangmawia, District Child Protection Officer, District Child Protection Society, SWD, Government of Mizoram.

ii) *Back translator (Mizo to English)*

Miss B.Lalhmingmawii, Programme Officer, State Child Protection Society, SWD, Government of Mizoram, Dr. Henry Z Pachuau, Assistant Professor, Social Work Department, Mizoram University, Miss Lalruatkimi, PhD research scholar, Social Work Department, Mizoram University.

Focus Group Discussion was conducted with Persons with Physical Disabilities from the urban core. The first group had eight participants, four participants each from both the gender. Differently Abled Society (DAS) was contacted for selecting the participants. The age of respondents was ranged between 20 to 50 years (see table 15). The second Focus Group Discussion was held among Persons with Physical Disabilities in the urban periphery. There were ten participants, five participants each from both male and female. Disabled People's Organization (DPO) under CBR Project was contact for selecting the participants. Their age ranged between 18 to 80 years (see table 16). The third group FGD was conducted Focus Group Discussion among People with Physical Disability was conducted in order to understand the issues and challenges of marriage faced by Persons with Physical Disability. There were nine participants, five of them were males and the other four participants were females.

Services and Opportunities mapping was conducted among men and women with Physical Disabilities separately from the urban core and urban periphery. Male participants of the urban core and urban periphery assemble in one place and female participants of the urban core and urban periphery at another place. There were nine participants (males=5 and female=4) across the Veng/Khua/Locality.

Assurance was given to the respondents in the study about confidentiality and respondents consent was obtained verbally.

3.5 Data Processing and Analysis

The quantitative data collected through interview schedule was processed with the help of computer packages of Microsoft Excel and SPSS package. To analyze the data, frequency, cross tabulation, averages and proportionate percentages was used. Karl Pearson's coefficient of correlation was also used. Data collected from Focus Group Discussions and PRA

exercises was analyzed and are presented in a summative form. Case vignettes are also presented with discussion.

3.6 Limitations of research

The research does not adequately represent the perceptions of the respondents because for hearing impaired and speech impaired the researchers had to rely on the care givers, parents or family members to interpret responses. A further limitation is that since many respondents were mostly not alone in the house while interviewing, it was observed that the respondents were hesitant to share their views and perception. Though much effort had been taken, collection of quality data required time on the part of the researcher, and also she observed that trust on the part of respondents was not easy to build because with such a short period of time rapport could not be built intensely.

CHAPTER IV

RESULTS AND DISCUSSION

This chapter discusses the results of the analysis of data collected through field survey at the urban Core and urban Periphery Veng/Khua/Locality within Aizawl District. The present chapter presents the socio-demographic profile of the respondents, their Social Support, Quality of Life and Psycho-Social Challenges.

4.1 Socio-demographic profile

This section presents the socio-demographic profile of the respondents. The profile include age-group, marital status, educational level, family structure, religion and denomination (See Table1).

4.1.1 Age-group

Age is an important variable when studying the profile of the respondents particularly in a study that involves disability. The age-group of the respondents is classified into Young (18-35 years), Middle (35-60 years), Old (60 years and above). *The mean age of the respondents was 46.3 years. There is no significant difference in the mean age across gender.* Half (51.0%) of the respondents were in the middle age. A fourth (25.5%) of the respondent were in the young age group and a little less than a quarter (23.5%) falls under the old age category. In the middle age group, there were more male (55.2%) than female (45.0%). However, in the young age-group and old age-group category, female respondents constitute a higher percentage than male respondents.

4.1.2 Marital status

Marital status is also another important variable in understanding the situation of the respondents. The statuses were categorized as married, never

married, divorced, widowed and single parent. *Almost half (49.5%) of the respondents were unmarried. In this category there were more males (53.4%) than females (43.8%).* More than a quarter (28.1%) was married and under this category interestingly there were more male (32.8%) than females (21.3%). A tenth (11.3%) of the respondents were however *divorced* and here there were more females (10.3%) than males (10.3%). *Almost a tenth (9.2%) of the respondents were widowed. In this category, females constitute a significantly higher percentage (17.5%) than males (3.4%).* Lastly, *single parent constitutes few respondents (2.6%) and only a small number of females (6.3%) fell under this category.*

Unlike the findings of Fairchild (2002) & Meekosha (2004) where females were likely to be unmarried, in this study we find that more males were unmarried than female. Like the findings of the present study, Meekosha (2004) in its study also reported that women with disabilities were more likely to be divorced than men. The NSSO survey reports that much more than a third (43%) of Persons with Disabilities in India were never married, while 39 per cent were married and 15 per cent of them were widowed and around 1 per cent were divorced or separated (as cited in Chaudhari, 2006). The result of the present study is also comparable with the study conducted by Hosain, Atkinson, and Underwood (2002), who found that more females with disability than males with disability reported that they cannot marry. However, more males than females delayed their marriage and divorce was higher among female respondents.

4.1.3 Education

Education of a person is important in studies of this nature as they indicate opportunity to employment etc. Educational level will highlight the availability and accessibility of education to the respondents. Educational level of the respondents were classified into eight levels viz., illiterate, nursery,

primary, middle, high school, higher secondary, graduate, post graduate and special school.

Those respondents who reached only till the *nursery level* constitute the highest percentage (23.5%). In this category, there were more females than males. This was followed by respondents (23%) who were *illiterate* and there were more illiterate females (27.5%) than males (19.8%). Further, respondents who studied till the *primary level* constituted 19.4 per cent of the sample. There were more males (20.7%) than females (17.5%) who fell under this category. Respondents who reached the *middle level* of education constituted 18.4 per cent. In this category, there is no significant difference in gender. Less than a tenth (9.2%) of the respondents studied till the *high school* level and there were more males than females. Similarly, only a small per cent (3.1%) of the respondents reached *higher secondary level* and in this level there were more males (3.4%) than females (2.5%). Further, only 2 per cent of the respondents were *graduate* and there were more females (2.5%) than males (1.7%). Only females (1.3%) were *post graduate* and only males (1.7%) studied in *special school*.

From this finding, we see that as the level of education increased, the number of respondents decreased. We also find that the educational level of females till the higher secondary stage is lower than males. This shows that females' access to education is less as compared to males particularly when they have a disability. However, we also find that as the level reached the graduate stage, there were more females than males. At the same time, the present study does not cover the reason for decrease in higher studies, the present findings could be related with the findings of Sylvester, Donnell, Grey, Higgin & Stalker (2014), it stated that "expectations of achieving academic qualifications and moving into further or higher education were generally low" (p. 763). The present findings also confirm the results of the NSSO survey. *It reports that among the Persons with Disabilities who were illiterate, large*

sections were only educated up to primary and middle level” (as cited in Chaudhari, 2006, p.12).

4.1.4 Family Characteristics

Family is one of the most important subsystems of a society and contributes in determining the Quality of Life and support system of Persons with Physical Disabilities. The structure of family viz. type of family, form of family and size of family are discussed in this section. In this study on Quality of Life, it is an important determinant to understand composition and social support etc.

There were three types of family reported among the families of Persons with Physical Disabilities. They were *nuclear family*, *joint family* and *living separately/alone*. The findings showed that almost half (49.5%) of the respondents live in a *joint family*. There were more males (52.6%) than females (45.0%) in this category. This was followed by respondents (44.4%) living in a *nuclear family* and there were more females (50.0%) than males (40.5%) under this category. The findings also interestingly revealed that a significant minority (6.1%) of the respondents *lived separately* from their families and there were more males (6.9%) than females (5.0%) who live separately. *This directs attention to QoL and Social Support for PwDs.*

The form of family were classified into three categories viz., stable, broken and reconstituted. Majority (78.1%) of the respondents were from a *stable family*. In this category there were more males (81.0%) than females (73.8%). Less than a fifth (18.4%) were from *broken family*. Here, there were more females (23.8%) than males (14.7%) belonging to broken family. *Reconstituted family* also holds a small percentage of respondents (3.6%). There were more males (4.3%) than females (2.5%) in this category.

The size of family was classified into three categories viz., small (1-3 members), medium (4-6 members) and large (7 and above members). Half (52.0%) of the respondents were from *medium size family*. There were more

females (52.5%) than males (51.7%) who lived in this category. More than a third (39.3%) of the respondents lived in *small size family* and there were more females (43.8%) than males (36.2%) under this category. Only a small percentage (8.7%) of the respondent was from *large size families*. There were more males (12.1%) than females (3.8%) in this category. *The mean size of family was 4.2.*

4.1.5 Religion

Religion of the respondent is an important dimension in research in order to understand the social characteristics of the respondents. *Majority (99.5%) of the respondents were Christian.*

The denomination identified from the respondents were Presbyterian, United Pentecostal church, Salvation army, Roman Catholic, Seventh Day Adventist, Isua Krista Kohhran, Lairam Isua Krista Kohhran, Baptist and Israel. Respondents with no denomination were also identified. Respondents belonging to the *Presbyterian denomination* constituted more than half (63.8 %) of the sample size. Less than a tenth of each of the respondents was distributed among each of the remaining denominations.

Table 1: Socio Demographic Profile

Sl.No	Characteristics	Gender		
		Male	Female	Total
		n = 116	n = 80	N = 196
I	Age Group			
	Young (18 - 35)	28 (24.1)	22 (27.5)	50 (25.5)
	Middle (35 - 60)	64 (55.2)	36 (45.0)	100 (51.0)
	Old (60 and Above)	24 (20.7)	22 (27.5)	46 (23.5)
	Mean Age	46.4	46.2	46.3
II	Marital Status			
	Married	38 (32.8)	17 (21.3)	55 (28.1)
	Never Married	62	35	97

		(53.4)	(43.8)	(49.5)
	Divorced	12 (10.3)	9 (11.3)	21 (10.7)
	Widowed	4 (3.4)	14 (17.5)	18 (9.2)
	Single Parent	0 (0.0)	5 (6.3)	5 (2.6)
III	Educational Level			
	Illiterate	23 (19.8)	22 (27.5)	45 (23.0)
	Nursery	27 (23.3)	19 (23.8)	46 (23.5)
	Primary	24 (20.7)	14 (17.5)	38 (19.4)
	Middle	21 (18.1)	15 (18.8)	36 (18.4)
	High School	13 (11.2)	5 (6.3)	18 (9.2)
	Higher Secondary	4 (3.4)	2 (2.5)	6 (3.1)
	Graduate	2 (1.7)	2 (2.5)	4 (2.0)
	Post Graduate	0 0.0	1 (1.3)	1 (0.5)
	Special School	2 (1.7)	0 0.0	2 (1.0)
IV	Type of Family			
	Nuclear Family	47 (40.5)	40 (50.0)	87 (44.4)
	Joint Family	61 (52.6)	36 (45.0)	97 (49.5)
	Live Separately	8 (6.9)	4 (5.0)	12 (6.1)
V	Form of Family			
	Stable	94 (81.0)	59 (73.8)	153 (78.1)
	Broken	17 (14.7)	19 (23.8)	36 (18.4)
	Reconstituted	5 (4.3)	2 (2.5)	7 (3.6)
VI	Size of Family			
	Small(1 - 3)	42 (36.2)	35 (43.8)	77 (39.3)
	Medium(4 - 6)	60	42	102

		(51.7)	(52.5)	(52.0)
	Large (7 and Above)	14 (12.1)	3 (3.8)	17 (8.7)
	<i>Mean Size of Family</i>	4.4	3.9	4.2
VII	Religion and Denomination			
	Christian	115 (99.1)	80 (100.0)	195 (99.5)
	No Religion	1 (0.9)	0 0.0	1 (0.5)
VIII	Denomination			
	Presbyterian	80 (69.0)	45 (56.3)	125 (63.8)
	United Penticostal Church	8 (6.9)	8 (10.0)	16 (8.2)
	Salvation Army	9 (7.8)	10 (12.5)	19 (9.7)
	Roman Catholic	6 (5.2)	4 (5.0)	10 (5.1)
	Seventh Day Adventist	1 (0.9)	4 (5.0)	5 (2.6)
	Isua Krista Kohhran (IKK)	6 (5.2)	7 (8.8)	13 (6.6)
	No Denomination	2 (1.7)	0 0.0	2 (1.0)
	Israel	1 (0.9)	0 0.0	1 (0.5)
	Baptist	2 (1.7)	2 (2.5)	4 (2.0)
	Lairam Baptist Isua Krista Kohhran (LBIKK)	1 (0.9)	0 0.0	1 (0.5)

Source: Computed

(Figures in parentheses are percentages)

4.1.6 Economic Profile

The economic profile is another important variable for assessing the situation of the studied population. It is presented in terms of occupation; socio-economic category and average monthly income (see Table 2).

4.1.7 Occupation

The occupation of the respondents were identified as unemployed, government employee, agricultural work, business, daily labor, skilled work, private employee, pensioner, beggar and quarry worker.

The findings revealed that *unemployed constituted almost half (54.1%) of the studied population. In this category, there were more unemployed female respondents (71.0%) than males (42.2%).* A little more than a tenth (14.8%) was engaged as *daily laborers* and there were more males (18.1%) than females (10.0%). Less than a tenth each of the respondents was distributed among each of the remaining occupation.

The findings are similar with the findings of Harris Poll, who reported that 69 percent of people with disabilities in the US aged between 16 to 64 years were not working. Only 20 percent worked full time. Further, he also found that the rate of poverty and employment was higher among women with disabilities (as cited in Tower, 2003). In support of this discussion, according to NSSO survey in 2002, the work activity of the Persons with Disabilities was surveyed and the highest percentage constitutes “no work” which comprises almost half of Persons with Disabilities in both rural and urban areas (in Chaudhari, 2006, p. 13).

4.1.8 Socio-economic category

The socio-economic category of the studied population was classified into non-poor, poor, and very poor.

Nearly half (46.4%) of the respondents were *poor (BPL)*. In this category there were more females (47.5%) than males (45.7%). The respondents belonging to the *non-poor (APL)* constituted 44.4 per cent of the sample size and there were more males (45.7%) than females (42.5%). Those respondents belonging to the *Very Poor (AAY)* constituted less than a tenth (8.7%) of the studied population. In this category, there were more females (10.0%) than males (7.8%). *From here, we find that more than half of the respondents suffer*

from poverty. Kaye, LaPlante & Wenger in their study on disability reported that ‘across the board, the poverty rate increases substantially when a householder has a disability’ (as cited in Tower, 2003). The findings of Menon, Parish & Rose (2014) also stated that ‘households with individuals with disabilities have up to 14 per cent lower average monthly per-person spending as compared with families with able members’. The study by Kuvelekar, Kamath, Ashok, Shelly, Mavva & Chandrasekaran (2015) also show that more than half (62.3%) were found to be unemployed. Linton and Longmore also stated that “People with Disabilities have endured a long history of social isolation and employment discrimination” (as cited in Cook, 2011, p. 1).

4.1.9 Average monthly income

The average monthly income of the studied population is classified into minimum and maximum. From the tables *we find that the maximum average income of males who were employed was Rs. 20000/- and for females it was Rs. 15000/-.* The mean average monthly income also reflects this difference. *The total mean income is Rs 2332.5/- and male respondents monthly income is higher (Rs. 3288.8/-) than female respondents monthly income (Rs.1376.2/-)*

Table 2: Economic Characteristics

Sl.No	Economic Profile	Gender		
		Male	Female	Total
		n = 116	n = 80	N = 196
I	Occupation			
	Unemployed	49 (42.2)	57 (71.3)	106 (54.1)
	Government Employee	11 (9.5)	1 (1.3)	12 (6.1)
	Agricultural	10 (8.6)	5 (6.3)	15 (7.7)
	Business	6 (5.2)	4 (5.0)	10 (5.1)
	Daily Laborer	21	8	29

		(18.1)	(10.0)	(14.8)
	Skilled Worker	11 (9.5)	0 (0.0)	11 (5.6)
	Private Employee	1 (0.9)	2 (2.5)	3 (1.5)
	Pensioner	6 (5.2)	0 (0.0)	6 (3.1)
	Beggar	1 (0.9)	2 (2.5)	3 (1.5)
	Quarry Worker	0 0.0	1 (1.3)	1 (0.5)
II	Socio Economic Category			
	Non-poor(APL)	53 (45.7)	34 (42.5)	87 (44.4)
	Poor(BPL)	53 (45.7)	38 (47.5)	91 (46.4)
	Very Poor(AAY)	9 (7.8)	8 (10.0)	17 (8.7)
	No Response	1 (0.9)	0 (0.0)	1 (0.5)
III	Average Monthly Income			
	Minimum	0	0	0
	Maximum	20000.0	15000.0	17500.0
	Mean	3288.8	1376.2	2332.5

Source: Computed

(Figures in parentheses are percentages)

4.1.10 Disability Profile

The profile of disability is an important variable in understanding the nature and characteristics of the respondents, their history, accessibility to disability certificates and their physical challenges. Thus, the following section discusses the type of disability, possession of disability certificates and family history of persons with disabilities (see Table 3).

Almost half (47.4%) of the respondents were *hearing impaired*. In this category there were more males (53.4%) than females (38.8%). This category was followed by of the respondents who fall under *locomotor disability* (44.4%). In this category there were more males (44.8%) than females (43.8%). Further, respondents who falls under the category of *speech impaired* constituted a fourth (25.5%) of the studied population. Under this category

there were more males (30.2%) than females (18.8%). Last, the respondents who reported as suffering from *visual impairment* constituted a little more than a tenth (13.3%) of the studied population. Here, we find more females (18.8%) than males (9.5%). *From this finding, we notice gender variation in respect of type of disability.*

The possession of disability certificate is another important information when studying Persons with Physical Disability as it contributes in determining the resources availed by Persons with Disabilities.

From the findings we see that less than half (45.9%) of the respondents reported as *possessing disability certificate* out of which there were more females (50.0%) than males (43.1%) who possessed disability certificate. As a whole, the present findings have significance with the findings reported by World Bank in Uttar Pradesh, India where it states that 80 per cent of households with People with Disabilities were unaware of the process of certification (Menon, Parish & Rose, 2014).

Family history of disability is another important element for studying the situation of Persons with Physical Disability. This will highlight any possible history of disability in respondent's family. The family history of disability was categorized into grand parents' generation, parents' generation, respondents' generation and successive generation.

Respondents having *family history of disability* constituted a little more than a third (34.0%). More female respondents (35.2%) than male respondents (33.8%) have family history of disability. *From here we see that respondents' family history of disability was significantly high for both males and females.*

Among the four categories of generation we also find that history of disability in respondent generation (brother, sister, cousin) was highest (12.2%).

Table 3: Disability Profile

I	Type of Disability	Gender					
		Male		Female		Total	
		n = 116		n = 80		N = 196	
		Frequency	%	Frequency	%	Frequency	%
	Hearing	62.0	53.4	31.0	38.8	93.0	47.4
	Locomotor	52.0	44.8	35.0	43.8	87.0	44.4
	Speech	35.0	30.2	15.0	18.8	50.0	25.5
	Visual	11.0	9.5	15.0	18.8	26.0	13.3
II	Possession of Disability Certificate	50.0	43.1	40.0	50.0	90.0	45.9
III	Family History of Disability						
	Grand Parents' Generation						
	Grandfather	1	0.9	1	1.3	2	1.0
	Grandmother	0	0.0	0	0.0	0	0.0
	Parent's Generation	0	0.0	0	0.0	0	0.0
	Father	2	1.7	2	2.5	4	2.0
	Mother	1	0.9	4	5.0	5	2.6
	Uncle	1	0.9	1	1.3	2	1.0
	Aunty	1	0.9	1	1.3	2	1.0
	Respondents' Generation	0	0.0	0	0.0	0	0.0
	Brother	16	13.8	8	10.0	24	12.2
	Sister	8	6.9	5	6.3	13	6.6
	Cousin	1	0.9	0	0.0	1	0.5
	Successive Generation	0	0.0	0	0.0	0	0.0
	Son	4	3.4	2	2.5	6	3.1
	Daughter	2	1.7	2	2.5	4	2.0
	Niece	1	0.9	0	0.0	1	0.5
	Nephew	1	0.9	2	2.5	3	1.5
	Total	39	33.8	28	35.2	67	34

Source: Computed

(Figures in parentheses are percentages)

4.2 Social Support and Persons with Physical Disability

This section discusses the social support received by the studied population. The type of social support received by the respondents was categorized into three types of support viz. Emotional Support, Financial

Support and Instrumental Support and the supporters were categorized into three groups such as Primary group, Secondary group and Tertiary group.

4.2.1 Social Support: Primary Level

The primary level includes supporters from family, close friends and relatives (see Table 4). From the table, we see that majority (79.1%) received *emotional support from the primary level*. We find that there were more males (86.2%) than females (68.8%) who received emotional support. Majority (77.0 %) of the respondents also received *financial support and* there were more female (86.2.1%) than males (70.7%) who received this kind of support. Half of the respondents (54.1%) also received *instrumental support from the primary level*. There were more females (57.5%) than males (51.7%) who received this support. There were a few respondents (1.5%) who did not receive any type of support from the primary level. There were more females (2.5%) than males (0.4%) who fell in this category.

The present study result is comparable with the paper review by Alotaibi (1997) who states that "support from primary levels mostly provides emotional support such as love, care and fulfillment of personal needs, in addition to instrumental support that includes service and financial support".

Table 4: Social Support: Primary Group

Sl.No	Primary Groups (Family, close friends and relatives)	Gender		
		Male	Female	Total
		n = 116	n = 80	N = 196
1	None	1 (0.9)	2 (2.5)	3 (1.5)
2	Instrumental	60 (51.7)	46 (57.5)	106 (54.1)
3	Financial	82 (70.7)	69 (86.2)	151 (77.0)
4	Emotional	100 (86.2)	55 (68.8)	155 (79.1)

Source: Computed

(Figures in parentheses are percentages)

4.2.2 Distribution of Primary Level Supporters

Table 5 shows that more than a tenth (15.2%) of the respondents was supported by their *brothers*. Similarly, more than a tenth (12.9%) of the respondents was supported by their *mothers*. Further, a little more than a tenth (11.7%) of the respondents was supported by their *sisters*. *There is no significant gender differentiation*. Less than a tenth each of the respondents received support from the rest of the categories.

Table 5: Distribution of Primary Level Supporters

Sl. No	Primary Level Supporters	Gender				Total N=574	%
		Male		Female			
		n=348		n=226			
		Frequency	%	Frequency	%		
1.	Brother	51	14.7	36	15.9	87	15.2
2.	Mother	45	12.9	29	12.8	74	12.9
3.	Son	23	6.6	24	10.6	47	8.2
4.	Sister	46	13.2	21	9.3	67	11.7
5.	Daughter	36	10.3	20	8.8	56	9.8
6.	Father	26	7.5	17	7.5	43	7.5
7.	Spouse	36	10.3	17	7.5	53	9.2
8.	Friends	5	1.4	9	4.0	14	2.4
9.	Grandchildren	8	2.3	13	5.8	21	3.7
10.	In Laws	27	7.8	21	9.3	48	8.4
11.	Other relatives	5	1.4	5	2.2	10	1.7
12.	Cousin	6	1.7	4	1.8	10	1.7
13.	Nephew	6	1.7	3	1.3	9	1.6
14.	Uncle	6	1.7	2	0.9	8	1.4
15.	Neighbors	2	0.6	2	0.9	4	0.7
16.	Aunty	12	3.4	1	0.4	13	2.3
17.	Niece	3	0.9	1	0.4	4	0.7
18.	Grandparents	5	1.4	1	0.4	6	1.0

Source: Computed

(Figures in parentheses are percentages)

4.2.3 Social Support: Secondary Level

Secondary level supporters include church, YMA, MUP, MHIP, LC, ZEP, LPS, Presbyterian Hospital and Philanthropists (see Table 6).

The findings showed that more than half (56.1%) of the respondents did not receive any support from the church. More females (62.5%) than males (51.7%) did not receive any support. However, less than half (42.9%) of the respondents received financial support from the church. There were more males (46.6%) than females (37.5%). Only a very small number (1.7%) of males reported to have received instrumental support from the church.

Majority (85.2%) of the respondents did not receive any social support from the YMA. A little more than a tenth (12.2%) of the respondents received financial support from the YMA. No significant difference was found across gender. However, very few (2.6%) of the respondents received instrumental support from the YMA. There were more females (3.8%) than males (1.7%) who received the support. Further, we find that majority (88.8%) of the studied population did not receive any support from MUP. A tenth (10.7%) received financial support out of which there were more female (12.5%) than males (9.5%). Majority (89.3%) of the respondents did not receive any support from the MHIP. A tenth (10.7%) of the respondents received financial support. There were more females (16.3%) than males (6.9%) who received the same.

Table 6: Social Support: Secondary Level

Sl.No	Organization	Gender		
		Male	Female	Total
		n = 116	n = 80	N = 196
I	Church			
	None	60 (51.7)	50 (62.5)	110 (56.1)
	Instrumental	2 (1.7)	0 (0.0)	2 (1.0)
	Financial	54 (46.6)	30 (37.5)	84 (42.9)
II	YMA			
	None	100 (86.2)	67 (83.8)	167 (85.2)

	Instrumental	2 (1.7)	3 (3.8)	5 (2.6)
	Financial	14 (12.1)	10 (12.5)	24 (12.2)
III	MUP			
	None	104 (89.7)	70 (87.5)	174 (88.8)
	Instrumental	1 (0.9)	0 (0.0)	1 (0.5)
	Financial	11 (9.5)	10 (12.5)	21 (10.7)
IV	MHIP			
	None	108 (93.1)	67 (83.8)	175 (89.3)
	Financial	8 (6.9)	13 (16.3)	21 (10.7)
V	Local Council (LC)			
	None	114 (98.3)	79 (98.8)	193 (98.5)
	Financial	2 (1.7)	1 (1.3)	3 (1.5)
IV	Zoram Entu Pawl (ZEP)			
	None	115 (99.1)	79 (98.8)	194 (99.0)
	Instrumental	0 (0.0)	1 (1.3)	1 (0.5)
	Financial	1 (0.9)	0 (0.0)	1 (0.5)
VII	LPS (Local Cable Network)			
	None	115 (99.1)	80 (100)	195 (99.5)
	Financial	1 (0.9)	0 (0.0)	1 (0.5)
VIII	Presbyterian Durtlang Hospital			
	None	116 (100.0)	79 (98.8)	195 (99.5)
	Instrumental	0 (0.0)	1 (1.3)	1 (0.5)
IX	Philanthropists			
	None	115 (99.1)	80 (100.0)	195 (99.5)
	Financial	1 (0.9)	0 (0.0)	1 (0.5)

Source: Computed

(Figures in parentheses are percentages)

4.2.4 Social Support: Tertiary Level

Tertiary level includes Government agencies and schemes such as Social Welfare Department, SCERT, Police Department, NIOH, Public Work Department and New Land Use Policy (see Table 7). From this finding we were able to understand government intervention in the reintegration and rehabilitation of Persons with Physical Disabilities.

The table shows that majority of the respondents did not receive any support from the Government agencies and schemes. Less than a tenth (6.1%) received instrumental support from Social welfare department and a very small percentage (0.5%) also received financial support from the same department. A very small percentage (1.0%, 0.5%, 0.5 %,) also received instrumental support SCERT, Police Department and NIOH. There was no gender differences found from tertiary support.

From the above interpretation we see that the findings are similar with the study conducted by Singh, Sharma, Chandra, Nigam & Varma (2011) where majority (87.14%) of the studied population received support from their family and friends. However, unlike their findings where community support was highest i.e. 90.95 per cent, we see that in this present study, support from secondary and tertiary levels is least.

Table 7: Social Support: Tertiary Level

Sl.No	Organization	Gender		
		Male	Female	Total
		n = 116	n = 80	N = 196
I	Social Welfare Department			
	None	107 (92.2)	76 (95.0)	182 (92.9)
	Instrumental	8 (6.9)	4 (5.0)	12 (6.1)
	Financial	1 (0.9)	0 (0.0)	1 (0.5)
III	SCERT			
	None	114 (98.3)	80 (100.0)	194 (99.0)

	Instrumental	2 (1.7)	0 (0.0)	2 (1.0)
IV	Police Department			
	None	115 (99.1)	80 (100.0)	195 (99.5)
	Instrumental	1 (0.9)	0 (0.0)	1 (0.5)
V	NIOH			
	None	115 (99.1)	80 (100.0)	195 (99.5)
	Instrumental	1 (0.9)	0 (0.0)	1 (0.5)
VI	Public Work Department			
	None	115 (99.1)	80 (100.0)	195 (99.5)
	Financial	1 (0.9)	0 (0.0)	1 (0.5)
II	New Land Use Policy (NLUP)			
	None	114 (98.3)	78 (97.5)	192 (98.0)
	Financial	2 (1.7)	2 (2.5)	4 (2.0)

Source: Computed

(Figures in parentheses are percentages)

4.2.5 Overall Average Social Support of Primary, Secondary and Tertiary Levels

Table 8 shows the overall mean average of social support of the three levels; Primary, Secondary and Tertiary levels. *From the findings, we see that a clear majority did not receive any social support from the three groups put together.* There were some respondents who received multiple supports. Among those who received social support from the three groups, a little less than a tenth (9.1%) received financial support. This is followed by those (4.3%) who received instrumental support and those (3.8%) who received emotional support. In this overall evaluation, social support seemed less because secondary and tertiary levels' of support were very limited while support from primary level was found to be strong. Gender variation is not

found amongst the support groups. The result of the present study is comparable with the review of Alotaibi (1997) who states that informal network such as families and friends tend to be larger in size.

Table 8: Overall Average Social Support of Primary, Secondary and Tertiary Levels

Sl.No	Social Support	Gender		
		Male	Female	Total
		n = 124	n = 84	N = 208
1	None	102 (82.3)	70 (83.3)	172 (82.7)
2	Instrumental	5 (4.0)	3 (3.6)	8 (3.8)
3	Financial	11 (8.9)	8 (9.5)	19 (9.1)
4	Emotional	6 (4.8)	3 (3.6)	9 (4.3)

Source: Computed

(Figures in parentheses are percentages)

4.3 Quality of Life of Persons with Physical Disabilities

This section discusses the Quality of Life of Persons with Physical Disabilities based upon WHOQoL BREF. It contains a total of 26 questions and 24 facets. *There are four dimensions which are physical health, psychological, social relationships and environment.* The overall Quality of Life will be discussed followed by the relationships each dimensions have on each other and the determinants of Quality of Life and Personal characteristics of the respondents.

4.3.1 Overall Quality of Life across gender

Table 9 shows that the overall perception of the respondents across the domains is low. Among them, *environmental domain is found to be most consistent* followed by physical health, psychological health and social relationship. The table shows that in the physical health domain male

respondents scored higher mean (20.2) than their female counterparts (18.9).

Overall, there is few gender differentiation across the domains.

The present finding is also comparable with the findings of Chow, Lo & Cummins (2005) their findings reported that “no significant differences in any of the QoL scores were detected between males and females”.

Table 9: Overall Quality of Life across gender

Sl. No	Quality of Life	Gender							
		Male		Female		Total			
		n = 116		n = 80		N = 196			
		Mean	S.D.	Mean	S.D.	Mean	S.D.	t	Sig. (2-tailed)
1	Physical Health	20.2	4.6	18.9	3.1	19.7	4.1	-2.23	0.03
2	Psychological Health	19.0	2.6	18.9	2.6	19.0	2.6	-0.35	0.72
3	Social Relationships	10.4	1.9	10.5	1.6	10.4	1.8	0.31	0.76
4	Environment	23.8	3.0	23.2	2.8	23.5	2.9	-1.32	0.19

(p<0.05)

4.3.2 Relationship between Dimensions of Quality of Life

Table 10 shows that there is a correlation among the four dimensions of the Quality of Life of the respondents. In other words each dimension is found to influence the overall Quality of Life. The domains such as the overall Quality of Life and environment domains (0.50), psychological and social relationship domains (0.56) and psychological and environment (0.50) domains are strongly correlated. The remaining domains are moderately correlated with each other.

Table 10: Relationship between Dimensions of Quality of Life

Sl No.	QOL Dimensions	Overall Quality of Life	Physical Health	Psychological	Social Relationships	Environment
1	Overall Quality of Life	1	0.38	0.35	0.43	0.50
2	Physical Health	0.38	1	0.40	0.45	0.38
3	Psychological	0.35	0.40	1	0.56	0.50
4	Social Relationship	0.43	0.45	0.56	1	0.42
5	Environment	0.50	0.38	0.50	0.42	1

Source computed

(correlation is significant at the 0.01 level)

4.3.3 Determinants of Quality of Life and Personal characteristic

To understand the determinants of the Quality of Life of the respondents, the respondent characteristics and the Quality of Life domains were analyzed using Pearson's Co-efficient of correlation. The correlation coefficient between respondents' characteristics such as age, gender, educational status and monthly personal income and Quality of Life domains such as overall Quality of Life, physical health, psychological, social relationships and environment were analyzed.

Table 11 shows that the respondents 'characteristics of age has a negative significant relationship with the overall Quality of Life (-0.19), physical health (-0.25) and social relationships (-0.21). In other words higher the age lower is the overall Quality of Life, physical health and social relationships. The respondents characteristic such as gender has a negative significant relationship with the physical health domain (-0.15) of the Quality of Life. The educational status of the respondent however has a positive significant relationship with the overall Quality of Life (0.18), physical health (0.14), social relationships (0.17) and environment (0.24) domains. In other words higher the educational status of the respondents higher is the overall Quality of Life, physical health, social relationships and environment domains.

The *monthly personal income* of the respondents also has a positive significant relationship with the physical health (0.18), psychological (0.12), social relationship (0.13) and environment (0.22) domains. In other words higher the monthly personal income of the respondents higher is the physical health, psychological, social relationships and environment domains.

Table 11: Determinants of Quality of Life and Personal characteristics of the Respondents

Sl No.	Characteristics	Overall Quality of Life	Physical Health	Psycho-logical	Social Relationships	Environ-ment
I	Personal Characteristics					
	Age	-0.19	-0.25	-0.07	-0.21	-0.09
	Gender	0.06	-0.15	-0.03	0.03	-0.09
	Education Status	0.18	0.14	0.09	0.17	0.24
	Monthly Personal Income	0.07	0.18	0.12	0.13	0.22

Source computed

(correlation is significant at the 0.01 level)

4.4. Psycho-Social Challenges of Persons with Physical Disabilities

The section analyzes the Psycho-Social Challenges of Person with Physical Disabilities through qualitative approach by using Case studies, Focus Group Discussions (FGDs), Key Informants Interviews (KIIs) and Participatory Rural Appraisal (PRA).

The first section discusses the Case Studies conducted across gender and the second section discusses the Focus Group Discussion conducted among Persons with Physical Disabilities at the urban core and urban periphery across gender. The third section discusses the results of PRA viz., Services and Opportunities map conducted among Persons with Physical Disabilities across gender.

4.4.1 Case Vignettes

This section represents the Case Studies conducted among Persons with Physical Disabilities across gender. Seven case studies; four Women with Disabilities and three Men with Disabilities were taken for the present study. Case study is an important method for understanding the psycho-social challenges faced by Persons with Physical Disabilities. *All names used in the studies are fictitious.*

Case Study I: Mrs. Zuali, a visually impaired mother

The first case is of Zuali a visually impaired woman aged 40 years. When she was in the VIII standard she got married and dropped-out from school. She was visually impaired for the past 26 years. As reported by her the cause of her disability was due to some error in prescription of medicine. After several visits to the doctor her vision became worse and thereafter she became completely blind. Her main activity at home now is doing household chores and taking care of her family. Her children also take care of her and assist her whenever necessary. The financial situation of the family is poor. Her husband, the bread winner, is a taxi driver. However, unfortunately, he passed away in 2011 due to cancer. Even though her son is doing petty business, the family's financial burden has worsened as there are few other means to support her. As a result of this, seeing her child in despair, Mrs. Zuali's mother decided to help them out and give financial assistance. Mrs. Zuali's mother herself has been remarried to another man and it is not easy for her to continue to extending her support.

Attending church service is Zuali's main outlet for socialization and serves also as a coping strategy. However, the accessibility of the church, especially the church toilet is difficult and a factor that inhibits her regular attendance. According to Mrs. Zuali awareness on disability services that she obtained has been mainly through the non-governmental organization working within their community. She also reported that it would be helpful to make use

of media to give more awareness related to the programmes and services for the disabled.

Discussion

The above case study shows adequate support from family member results in a positive psycho social wellbeing. The study conducted by Li Li and Moore (1998) also states that self-esteem and emotional support from family and friends played important roles in the participants' adjustment to disability. Allen and Mor (1997) however states that the consequences of inadequate help may compromise individuals' ability to maintain a safe and reasonable quality of community living. The higher levels of social support and sense of mastery were associated with lower level of chronic stress. The lower the level of chronic stress, the better is the physical health and wellbeing.

“A comprehensive literature review also supported spirituality as a coping method among individuals experiencing a variety of illnesses” (Kaye & Raghavan, 2002, p. 231). Mrs. Zuali finds attending church services enjoyable but was uncomfortable with the physical infrastructure of the church. The similar finding was also observed by Doyle, Moffatt, Corlett, (1994) in London where access to respite and organized social outlets was strictly limited, particularly for people with complex disabilities. “Media acting as a social element succeeded in fulfilling its role of constructing a better attitude toward people with disabilities. Print media; act as an advocate for people with disabilities, with a major contribution toward enlarging knowledge about disability and a real understanding of this minority” (Ciot, & Hove, 2010, p. 537).

Case Study II: Mrs. Rini, a visually impaired housewife

Mrs. Rini is visually impaired. She is 60 years of age and visually impaired for the past 31 years following a medical problem involving her eye.

She is married and has four sons between the ages of twenty-four to thirty years of age. Her husband is government primary school teacher. Therefore, they were transferred often and have resided in various villages due to her husband's occupation. One of her sons is married and lives separately. As Mrs. Rini is the only female member in the family, she has to take up all the household chores and sometimes this makes her feel exhausted. Sometimes she feels bad about people's comments on her blindness. She is very hard-working and having no other support at home, she often does all the chores of the house. At times, she has to climb on the roof of her house to dry the washed clothes. At such times, neighbors disbelievingly said that her disability may not be too severe if she is able to do so much work.

Being visually impaired she has also been elected as a treasurer in the Disabled People's Organization, an organization which was formed by persons with disability themselves with the support by non-governmental organizations working for persons with disability within their community. She has had her education till primary level only; however she is seen to be an active member in her family and in the community. The family owns a taxi which they bought in 2012 and one of her sons drives it and he would drop and pick her up when she requires. Other than that she did not go out much. Being a mother of four sons she is very concerned about the career of her children. Therefore, she suggests improvement of existing programmes and promotion of income generating activities for persons with disability as well as for their families. As reported by Mrs. Rini she is not very much aware of the services and programmes meant for the disabled and the only awareness she had was through the non-governmental organizations working within their community.

Discussion

The above case illustrate that even if persons with disability can perform their daily tasks and roles very well, the community however is also

required to be very supportive or otherwise the reaction of the community sometimes may result in increased stress. In the case vignettes above it is obvious that Mrs. Rini has been able to perform not only her role in the family but her roles in the neighborhood and community exceedingly well. And yet the community members are almost disbelieving of her ability to perform so well. This shows how society itself constructs disability in society. Viemero and Krause (1998) in their study report that some individuals with physical disabilities do not cope very well in their everyday life, no matter how long they have had the disability. As seen from Mrs Rini case, she did not receive information or she is not very much aware of the services and programmes meant for Persons with Disabilities, the study is comparable with the study made by Doyle, Moffatt, & Corlett, (1994) they also found that only few of his respondents with disabilities received about careers or independent living. If efforts are made to raise community awareness and make better community support structures, the burden faced by persons like Mrs. Rini may be eased.

Case Study III: Ms. Dini, a person with locomotor disability

The third case is of a young woman named Dini with locomotor disability whose paralysis disallows the left side of her body from functioning properly. She is 18 years of age and is handicapped for the last 16 years which was due to an accident when she fell down the stairs. She was raised in a low-income female-headed household with 3 family members. Apart from her locomotor disability she has had epilepsy following the accident which makes her vulnerable to other accidents and due to this she has had to drop out from school when she was in the IX standard. During her epilepsy seizure in schools, she was taken care of by her school friends and teachers and this used to make her feel very sad and embarrassed. Her experience from dropping out from school and leaving all her friends also makes her emotionally sad and disappointed. Her main activity is taking care of household chores, cooking and washing.

Being single, Dini's mother has to go out and earn a living when at the same time she has had to look after her physically challenged daughter. This has resulted in great tension for the family as a whole. Dini expresses that the only services that they had availed and known so far were from NGO services rendered to them. However, they would be very pleased if the government could implement services such as day care centers for the Persons with Disability. To them the existing services and programmes would be more effective if the existing ones are delivered and reached the real people who are in need.

Discussion

Dini's case explained that the consequences of disability contributed to economic, social and emotional stress which disturbed the overall functioning of an individual. Inclusive education has been efficiently carried out in the state; however, from the above case it is important to note that some factors still operate in inhibiting and restricting Persons with Disabilities from attaining educational level. In the same way as suggested by Beckett (2009) *'the issue of equal access to good quality education, responsive to children's experiences and needs irrespective of class, race, gender, sexuality or disability, remains high on the research agenda'* (p. 317). At the same time, personal and home based care is highly suggested for future implementation.

Case Study IV: Mrs. Siami, a hearing impaired single mother

The case presented here is of a widow named Mrs. Siami, aged 54 years. She has mild impairment in hearing for the last 4 years. Her husband passed away about ten years ago and she has had to shoulder the responsibility of supporting her family and this gave her a lot of 'tension'. She has 3 children, one son and two daughters and one of her daughters is married. Mrs. Siami has only had an education up to primary level. Her son works as a daily laborer and since his income was not enough to support the family, she sells

vegetables door to door and from this she earns a small amount. With the support of the Disabled Peoples Organization and non-governmental organizations working within their community she has been given a loan of Rs 5000/-. She started poultry farming and after four months she has to pay back the loan without interest when she sold her poultry. As reported by her she has little awareness regarding governmental programmes and services for persons with disability. The only awareness she received was through the non-governmental organizations working within their community. Being the bread winner and being impaired in hearing she has faced many challenges in her work place, when knocking door to door asking whether the household wants to buy vegetables the challenge is that she would not hear the persons reply of whether they say yes or no. She expresses that being not able to hear people make her feel embarrassed. She suggests promotion of income generating activities for poor households with Persons with Disability that could enhance and augment the livelihoods of the poor families that also had members with disability.

Discussion

The above case clearly describes that persons with disability can play their role very well despite their disability. It is important to remove the handicaps of Persons with Disability by providing suitable environment which is barrier free. Also a flexible and meaningful income generating activities in order to enhance their livelihood is required. Siami's case also shows that unmet needs prevailed among the persons with disability in the community and most of the services they received were mainly through CBOs or NGOs. Thus, this shows the importance of CBOs or NGOs in working with people with disability. Therefore, channelizing their activities by giving educational awareness to the Persons with Disability will be of much help. This will empower Persons with Disability; it will also provide a gate for improvement

in the availability and accessibility of resources for the Persons with Disability.

Case Study V: Mr. Sawma, the stone crusher

The fifth case study was Mr. Sawma aged 51 years. He is married and has two children. He was hearing impaired for more than 10 years. According to his perception his disability was caused due to an accident. Though hearing impaired, Mr. Sawma was engaged in many activities. He took an active leading role in unit of political party, church activities and disability association. However, being hearing impaired, he explained the challenges he faced by mentioning that being active in groups and organizations etc. he became members in the executive committee etc. and there are many a times when they had meeting and other important gatherings, but he used to be ashamed of himself for many a times he could not hear what others are discussing and therefore he would not attend. Mr. Sawma mentioned that he availed disability pension, but he himself was not very clear of the disability pension scheme and his resources are too limited for in-depth understanding of the available schemes so as the government services.

Discussion

It was evident from the above case study that people with disabilities have the capacity to survive in the society. However, the case study also reveals that they have low self-esteem due to their physical limitations. An article written by Rumsey & Harcourt (2004) also states that *physical disfigurement has psychological impact, Quality of Life and self esteem upon the individual.*

Case study VI: Mr. Ringa, the Butcher

The sixth case is of Mr. Ringa who is 50 years of age. He has been visually impaired for the past 40 years due to an accident. He was married and

currently there are 8 members in his family. He is a butcher and his friends were of great support in assisting him when required. He is an ex-president of the Disabled Peoples Organization that functions within their community through the support of CBR Project under Zoram Entu Pawl (ZEP). He mentioned that due to his visual impairment he was hesitant to have direct contact with others and he was uncomfortable in the public places as he had a low body image and ashamed of his physical appearance.

Discussion

The above case study reveals that People with Disabilities often express having a low body image. They fail to recognize disability as a form of human variability that for many people it is a source of pride, personal growth, identification and affiliation (Tower, 2003).

Case Study VII: Mr. Mala, poultry framer

The last case study was Mr. Mala was visually impaired and was 50 years of age. He is divorced and he lives alone. According to his perception the causes of his disability was hereditary and he had his disability for 26 years. He makes his living by engaging in poultry farming. In Mizo society whenever death takes place neighbors and relatives gather in the house, they would sing a song and some will have a short sermon to console the bereaved family. It is also a place where people socialized and meet friends. Mr. Mala also mentioned that he was interested in attending those gatherings. However, since he was blind he needs assistance of others to guide his way, so many times there are good people who offer him assistance. But he felt that he was a burden for others and therefore he discontinues attending many of the gatherings. He also mentioned that Persons with Disabilities are well accepted in the Mizo society, however according to him to receive help and assistance from the non-disabled person is more like an act of sympathy and pity. If

PwDs are act beyond the expectation of the society, they are not well accepted.

Discussion

The above case study clearly shows the attitudes of the society towards Persons with Physical Disabilities. Tower (2003) in an article discusses how People with Disability continue to use acquiescence or normalization as their strategies for living with disability. Acquiescence works because modern society usually accepts some responsibility for caring for its most vulnerable members. But this strategy lasts only as long as the person is willing to behave according to expectations, namely to be good and to be non-complaining attitude. However, Maximization of one's potential regardless of the societal expectation is needed.

4.4.2 Results of Focus Group Discussions

The main objective of FGD was to understand the Psycho-Social Challenges faced by Persons with Physical Disabilities in terms of economic, employment, family. An interview guide was prepared and it was used to facilitate the discussion (see Appendix 4). There were some similarities as well as differences in response from the groups. The participants were also assured of confidentiality and the purpose of the Focus Group Discussion was clearly explained at the beginning. The lists of participants are given in table 12 & 13.

4.4.2.1 Economic participation and Persons with Physical Disabilities

Despite their disability they said that they were willing to work for their own living without depending on others. Most of the respondents were engaged in minor occupation with meager monthly income. The meager income could hardly support their needs such as good medical treatment, access of quality aids and appliances etc. Many of the participants perceived

their disability was worsening due to poverty and inability to access quality health care. The participants agreed that the economic service provided for Persons with Physical Disabilities was not sufficient enough to meet their needs. They mentioned that services for the welfare of Persons with Physical Disabilities exist but in reality it did not meet their needs. The participants also mentioned that they do not want to use their disability as an advantage to gain something good out of it, however, all the participants asked for a fair and square implementation of services for better end results. They suggested that-

- 1) Reservation of posts for Persons with Physical Disabilities should be effectively implemented.
- 2) Income generating activities should be introduced irrespective of different types of disabilities and capabilities.
- 3) Programme and services introduced for Persons with Physical Disabilities should reach the needy. However, in many of the government programmes and services only the person belonging to BPL can avail such services.

4.4.2.2 Social participation and Persons with Physical Disabilities

Most of the participants from both the groups indicated that they were mostly too timid to participate in social activities. They further pointed out their own perceptions of 'body image' because disability stops them from participation in many social activities. They were not comfortable to get involved in public life due to their physical inability. Since, Mizoram is a state dominated by Christians, majority of the participants agreed that church is the place where they find their happiness; it is a place where they socialized to get away from the conscious reminder of disability. However, they mentioned that the church was not too sensitive to the needs and challenges of Persons with Physical Disabilities. They all faced challenges regarding barriers in the environment within the church premises. Some of the participants report that they had expressed the situation to the church elders; the necessity of making

church friendly for Persons with Physical Disability but the church elders are not yet to pay attention. Though many churches observed disability day every year, development cannot be seen in Quality of Life of PwDs. The recognition of Persons with Physical Disability by the church was mainly in terms of financial assistance which is mostly one time assistance with a very small amount. Therefore, church seemed to be oriented towards charity and welfare to some extent.

Support for Persons with Physical Disabilities within the community is mainly carried out by community organizations such as YMA, MUP, MHIP etc. Most of the participants were active members of the church and some of them were even members of important committees within the church. However, the participation in church was not satisfactory. Due to their physical limitations, they were not active participants in the church, they desired for the church elders visit which is often not done by the church elders. Some of the participants mentioned that they do not think of themselves as less abled and that their disability was just a different physical look and their disability did not stop them from their social participation, but the physical set up limits their participation. All the participants concluded that though Persons with Physical Disabilities were recognized and looked after by the society, much awareness was still needed to be carried out to help people to have right attitudes towards disability.

Many of the participants also expressed their interest in sports and some of them were engaged in different sports discipline but they continue to report that there was less opportunity for them in sports and the government and society were not well aware of inclusion of disability in sports.

It was observed that the community response to disability was different according to the locality that they resided in. In some community Persons with Physical Disabilities were given opportunities for participation in some neighborhoods. However, limitation of barrier free environment in public places often limited their participation.

4.4.2.3 Education and Persons with Physical Disability

Majority of the participants were under matriculation. The participants agreed that the present education system should be framed according to the needs of Persons with Disabilities. They mentioned that earlier some students with disability were teased by the non-disabled students and imitate the way they walk, speak etc. However, as a result of inclusive education and awareness on the rights and dignity of Persons with Disability a great improvement can be seen in terms of changing attitudes of the non-disabled children and teacher towards students with disability. But they mentioned that the facilities in educational institutions were still inadequate and unfriendly for students with disability. They longed for a disability friendly learning material and equipment.

4.4.2.4 Personal response to disability and coping strategy

In both the focus group discussion, the participants' perception regarding their disability was also discussed. The participants from both the group mentioned that when they first recognized their disability, it was hard to accept the fact and many of them denied the fact. But in due course of time they gradually accepted their disability and most of the participants mentioned that they tried to find a purpose and meaning in life. Some of them volunteered themselves and worked towards the welfare of their fellow Persons with Physical Disabilities and some of them were trying to be self-dependent by earning their own income. Many of the participants reported that the conscious thought about their physical appearance hampered further development.

However, they also agreed that religion was the most important coping strategy for them. Church was a place where they find peace within themselves and a place where they are able to go away from the conscious realization of their disability.

4.4.2.5 Societal attitudes towards disability

The participants agreed that earlier the perception and attitudes towards disability was adverse. Even in schools they were discriminated against and stigmatized by their fellow students but at higher level of education they faced less discrimination and stigmatization. The participants also reported that even in the community some non-disabled children used to imitate the way they walked in front of their children. Some of the hearing impaired participants also mentioned that some people when talking to them have the habit of speaking loudly near their ears which according to them is very unnecessary and embarrassing. At the same time, many of the participants mentioned that they often received instrumental support such as physical assistance and material assistance from their neighbours. They concluded that while Persons with Physical Disabilities were respected by the society, a positive attitude towards disability is still needed to be engrained. Majority of the respondents mentioned that they received good support from their family. Some of the participants also suggested making use of media for promoting the rights of Persons with Physical Disabilities in Mizoram.

The third Focus Group Discussion was monitored and facilitates in order to give participation for each of the participants across gender.

- i. Both males and females participants were open to marriage if they can find partners who could understand and accept them regardless of their disability. However, female participants were more towards being 'without partners'.
- ii. Both male and female also agrees that the advantage of being married is that they have partners who could look after them and take care of them. In their opinion, being looked after by parents or siblings could be a huge burden for the family.

- iii. Depending on others due to their disability makes them reluctant to also get married. Both males and females agreed that there are certain restrictions to marriage if a person's disability is not compatible to enter into marriage life. At the same time, the fear of losing partner after having a child also makes them reluctant to get married; being single and being disabled with children to look after can create a lot of challenges for themselves as well as for their families.
- iv. The fear of not able to provide the needs of their children also makes them want to be out of marriage.
- v. Divorce according to the opinion of both the participants is that a person who is disabled after their marriage does not result in divorce. In other words, disability does not contribute to divorce. According to female participants divorce usually happens when the other person is having extra marital affairs or is under the influence of substances such as drugs, alcohol etc.
- vi. The participants in both groups mentioned that like all other married couples, married persons with disabilities also faced certain challenges in terms of parenting, maintenance of family etc. One of the hearing impaired participants mentioned that "*Nupa a fate chungchang thu pawimawh sawi dawn pawh in ring tak tak a in biak a ngaih thin avangin midang in anlo hriat ve phah thin a a buaithlak thin hle*" in order to be audible, people had to speak to him loudly, but when it comes to family matters, in cases where the couple had to discuss about family matters or matters related to their children, their conversation become audible to all the people who are near them. This creates a lot of challenges.

Discussion

While the male participants from both the groups had similar response, the variation in responses was observed across gender. The male participants were more aware of their rights and discussion on the topic laid down was mostly discussed in terms of rights based approaches and they were more policy oriented. The female participants had their discussion in terms of their immediate need such as the need of medicine, easy accessibility of medical treatment, income generating activities to meet their immediate needs etc. It was also observed that the participants in both the groups showed a strong bond between themselves. They work towards their survival and Quality of Life to the best of their capacity. It was also observed that though the societal attitude towards disability is improving, their position in the society was far from satisfactory. However, it was observed that family played an important role for the growth and development of Persons with Physical Disabilities and it was seen that the participants received good support from their family.

The results of the focus group discussion also helped to understand the importance of the church in tackling the psycho-social challenges of Persons with Physical Disabilities. Church elders should be included in all the policy and programme related matters for Persons with Physical Disabilities. It was also observed that majority of the participants were not aware of the government services and programmes for the benefit of Persons with Physical Disabilities. The ones who were aware of it were not aware of the procedure. They did not know how to apply for such services and programmes. The participants also suggested that the selection of disability pensioner should be more uniform and realistic and suggested that the pension should be received by Persons with Severe Physical Disabilities who could not earn a living. It was also suggested that since majority of the participants mentioned poverty as their main obstacle for availing good health care facilities, even for the self-dependent income earner, their income was far too less to avail good medical treatment that they often needed, therefore, it was suggested that the

government and NGOs should plan a good policy for reliable health insurance for Persons with Physical Disabilities.

The discussion also reveals that Persons with Physical Disabilities were open to marriage if one can find partners who could accept them as they are. However, the fear of not being able to support their children, the fear of being a burden for other family members hesitate them to get married. A study conducted by Kuvelekar, Kamath, Ashok, Shelly, Mavva, & Chandrasekaran (2015) also mentioned that physical disability had affected marriage of PwPDs.

From the focus group discussion it was also observed that the society's approach in recognizing Persons with Physical Disabilities needs to be changed. Their recognition was mainly based on giving charity in times of a special event or programme. Approach towards further development and self-sustenance of Persons with Physical Disabilities is still lacking. As suggested by Cobley (2013), media should be used as a source for bringing positive change for the welfare of Persons with Physical Disabilities. Lastly, from the focus group discussions, it was observed that Persons with Physical Disabilities are a part of strong sub groups, and if positively nurtured, it can be used as an important force for bringing change in the Quality of Life of PwDs.

4.5 Result of Key Informants Interviews

The in-depth interview of people who are most knowledgeable to provide information or needed information regarding the issue of Persons with Physical Disabilities was carried out for understanding the current situation of Persons with Physical Disability. Probing and controlled conversation was utilized for generating information of the KIIs. In some case repeated interviews was held.

The distribution of KIIs consisted of Social/Human rights activists, Disability rights activists, church leaders, community leaders, government

officials, CBR project coordinators and field staff and Disabled Peoples' Organization (see table 15).

The KI interview guide consists of the following key questions (see also Appendix 4)-

- Implementation of the Mizoram Persons with Disabilities (Equal opportunities, Protection of Rights and Full participation) Rules 1999.
- Challenges faced by Persons with Physical Disabilities at the levels of Micro, Mezzo and Macro
- Support systems and services for Persons with Physical Disability
- Suggestions and Recommendations

4.5.1 Response of Key Informants Interview

KIs	Response to the Key Questions
Social/Human rights activist	<ul style="list-style-type: none"> • The implementation of PwD Rules, 1999 was a milestone for the development of Persons with Physical Disabilities in the society. • PwD Rules, 1999 was even called by many as 'Dan Rangkachak' (Golden Rule). However, the implementation is so unsatisfactory and became a 'Rusted Rule' • The challenges faced by PwDs are due to the fact they were not fully accepted by the society. • In some cases parents of the PwPDs were too over protected that it hampers the growth and development of their children with disability. • PwPDs mostly received good support and acceptance from their family as compared to the society.

	<ul style="list-style-type: none"> • Mostly the assistance/service received by the PwPDs from the society as well as the government is mainly in terms of small amount of money which hardly even meets their immediate need. • Efficient government officials having experience in the field of disability are needed for the development of PwPDs in the state.
Disability rights activist	<ul style="list-style-type: none"> • The implementation of PwD Rules was unsatisfactory. • Employment reservation mentioned under the rule was not effectively implemented by the government. • Much effort is needed to be carried out in creating barrier free environment for PwPDs. In particular Persons with Physical Disability still faced discrimination in terms of accessible and available facilities in public places etc. • The awareness level on the rights and dignity of PwDs were still limited among the general population. • The church and the government also need to be more sensitized regarding the issues of PwPDs. • There is a need to revised the definition of three percent reservation for PwPDs. Clear cut explanation should be given for the benefit of unemployed PwPDs.

Government officials	<ul style="list-style-type: none"> • Due to lack of manpower, services for PwPDs could not be satisfactorily carried out to meet the growing needs of PwPDs. • The government officials regret to mention that assistance such as NHDFC loan introduced for the development of PwPDs could not be continued for the time being due to some irresponsible loanee who failed to return their loan interest. • Poor data-based creates problem in working towards the welfare of PwPDs. Thus, important data in relation to disability is expected to be improved in the near future. • The nodal department i.e. Social Welfare Department has been carried out assessment cum certification camp in collaboration with line departments (SSA, SCERT, NIOH, Health Department). This effort is expected to bring better results for PwPDs.
CBR Project Coordinators and field workers	<ul style="list-style-type: none"> • The implementation of PwD Rule, 1999 is not satisfactory at various levels. • There is a good response from the community and parents to the project. • Parents of Children with Disability were observed to be over protective towards their children with disability • Limited funds sometimes delayed their work in reference to the project. • Since, CBR Project worked at the grassroots level, they know very well of the real situation of

	<p>PwPDs. Therefore, they recommended that the government should include and consult them in planning programmes and services for PwPDs.</p>
<p>Disabled Peoples' Organization (DPOs), Tlangnuam Block</p>	<ul style="list-style-type: none"> • Effective implementation of PwD Rules, 1999 is recommended in terms of service delivery etc. • Since, most of the PwPDs are with no proper means of income. The government should stress its programmes and services by creating income generation activities for PwPDs and their families. • As most of the PwPDs were living on meager means of support, most of them could not avail quality health care due to poverty. Therefore, the government should also introduced health care services within the reach of PwPDs. • Since many of the PwPDs were less educated, the government should simplify the procedures of its programmes and schemes.
<p>Church elders</p>	<ul style="list-style-type: none"> • 'Disabled Day' is observed by churches in Mizoram annually. The observance depends by denomination. • On the day listed above offerings of money by church members and parish are distributed to all PwPDs within the parish • Awareness and sensitization towards PwPDs is the main focus of the sermon by the pastor/church elders etc on the 'Disabled Day'.

Discussion

The KIIs of the present study show that the implementation of PwD Act was still seen as unsatisfactory. Service delivery still needs to be

strengthened and at the same time non-governmental organizations as well as community based organization etc working for Persons with Physical Disabilities must be empowered and strengthened. While the government is making an effort for collecting and maintains data-base with reference to disability, it is very much important to monitor the accuracy and reliability of data. Welfarists and charity based approaches are still observed by churches.

4.6 Participatory Rural Appraisal (PRA)

Services and Opportunities mapping was done both at the core and periphery Veng/Khua/Locality. It helped in understanding the challenges faced by Persons with Physical Disabilities and the level of their knowledge and information related to disability services. The lists of participants are given in table 14.

Figure 1 shows the Services and Opportunities map done by male participants of the urban core and urban periphery. From the figure, it was seen that male participants from both the Veng/Khua/Locality noted out fifteen service providers such as NGOs, CBOs and Government departments where Persons with Physical Disabilities can avail and access their services.

Figure 2 shows the Services and Opportunities map done by female participants of the urban core and urban periphery. During the conduct of PRA among female participants, it was observed that women are having less information than their male counterparts. From the figure, it was seen that women were aware of the service providers only with whom they have direct benefit. They noted only seven service providers.

Discussion

PRA of the present study shows that women with disability are much less informative than their male counterparts. It was evident that men with physical disability have more opportunities for access of services and resources.

Figure 2: Services and Opportunities map done by Men with Disability from both the urban core and urban periphery Veng/Khua/Locality.

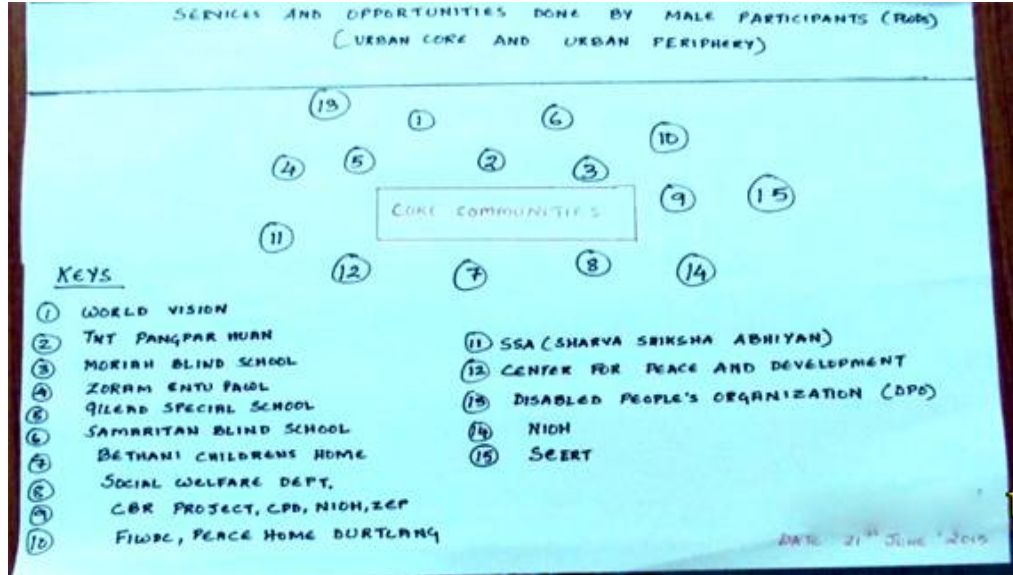
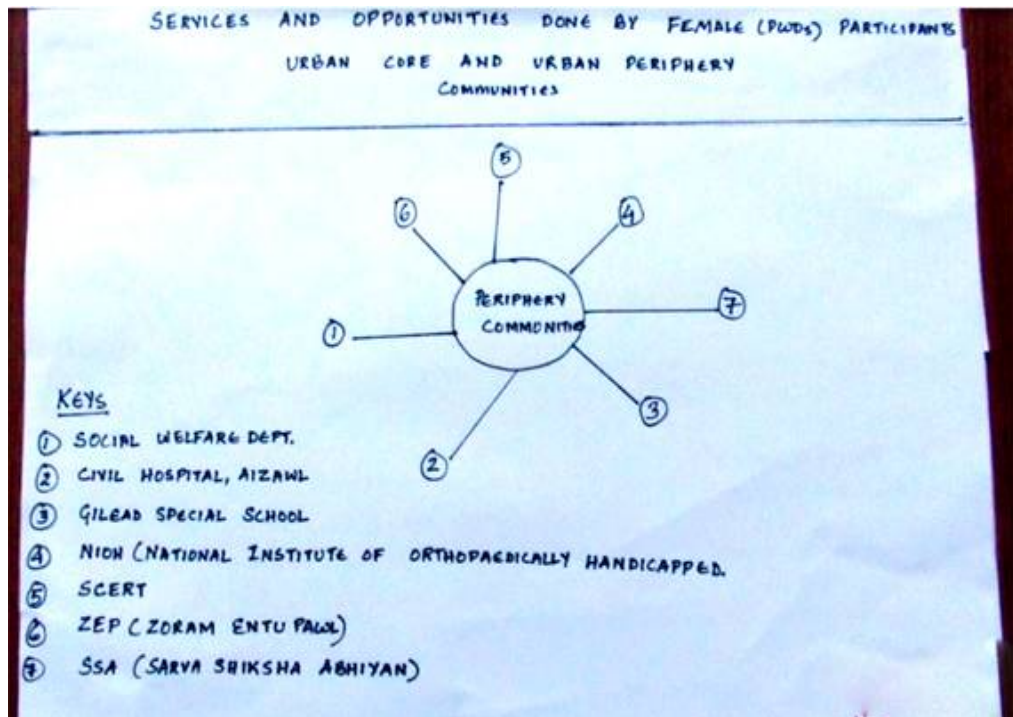


Figure 3: Services and Opportunities map done by Women with Disability from both the urban core and urban periphery Veng/Khua/Locality.



CHAPTER V

CONCLUSION AND SUGGESTIONS

This chapter presents the summary of the study and presents a discussion of its major findings. From the findings of the study, suggestions are highlighted to impact policy making and direct services from a social work perspective.

This study explores the Quality of Life and social support of Persons with Physical Disabilities. It seeks to profile Persons with Physical Disability in Aizawl, Mizoram. Examine their Psycho-Social Challenges, find the Quality of Life across gender, assess their social support and suggest measures for policy making and for social work intervention. The previous chapter presented the results of quantitative and qualitative data and discusses these results in the light of the results and relevant literature.

The methodology employed is cross-sectional in nature and exploratory in design. The study employed both quantitative and qualitative study. A multi-stage sampling was used for selection of the communities and the respondents. Communities from Tlangnuam Block, Aizawl District collected by CBR Project, NIOH & MZU were used. The community was filtered in order to meet the operational definition of the study. The communities were divided into Core communities and Peripheral Communities based on their vicinity (15 km approx.) from the center of Aizawl City i.e Treasury Square, Aizawl. Then the final Veng/Khua/Locality (core and periphery) were selected taking into consideration the gender population, distribution and proportion of Persons with Disabilities in each Veng/Khua/Locality.

The main conclusion in this study is being presented in relation to the objectives of the present study.

5.1 Profile of Persons with Physical Disabilities

The mean age of the respondents was *46.3 years*. There was no significant difference in the mean age across gender. *Overall, the respondents were in the middle age*. A fourth of the respondents were in the young age group and a little less than a fourth falls under old age category.

Almost half of the respondents were never married. Interestingly as compared to other studies, there were more males than females who were never married. A tenth of the respondents were however divorced and here there were more females than males. Almost a tenth of the respondents were widowed and females constitute a significantly higher percentage than males. Lastly, few respondents were single parent and more often, female fell under this category.

Nearly a fourth of the respondents were illiterate and there were more illiterate females than males. Similarly, a fourth of the respondents studied till the nursery level. The findings also show that Persons with Physical Disabilities mostly attained their education till primary and middle school level. Less than a tenth of the respondents studied high school level and there were more males than females. Only a small percentage of the respondents reached higher secondary level and in this level there were more males than females. Further, only two per cent of the respondents were graduate and there were more females than males. Only females were post graduated and only males studied in special school which constitutes a very small percentage.

The findings showed that almost half of the respondents live in a joint family. There were more males than females in this category. This was followed by respondents living in a nuclear family and there were more females than males under this category. The findings also interestingly revealed that *a significant percentage of the respondents lived separately from their families* and there were more males than females who lived separately.

Majority of the respondents were from a stable family. In this category there were more males than females. Less than a fifth were from broken

family. Here, there were more females than males. *The mean size of family was 4.2.* Half of the respondents were from medium size family. There were more females than males who lived in this category. More than a third of the respondents lived in small size family and there were more females than males under this category. Only a small percentage of the respondents were from large size families.

There were more males than females fell in this category. Respondents belonging to the Presbyterian denomination constituted more than half of the sample size. Less than a tenth each of the respondents was distributed among each of the remaining denominations. Respondents with no denomination were also identified.

The findings revealed that *more than half of the studied population was unemployed.* In this category there were more unemployed female respondents than males. More than a tenth was engaged as daily laborers and there were more males than females. Less than a tenth each of the occupation was distributed among each of the remaining occupation of the studied population. *Nearly half of the respondents were from poor socio-economic background.* In this category there were more females than males. Those respondents belonging to the Very Poor constituted less than a tenth of the studied population and there were more females than males. The findings of the present study also show that the mean monthly income of the responds was Rs 2332.5. Gender variation can be seen; *male respondents earn more monthly income than female respondents.*

Almost half of the respondents were hearing impaired. This category was followed by respondents who fall under Locomotor disability, speech impaired and visually impaired. From this finding we see gender variation in respect of type of disability. The present findings also reports that *less than half of the respondents were reported as possessing disability certificate* out of which there were more females than males who possessed disability certificate.

The family history of disability was categorized into grand parents' generation, parents' generation, respondents' generation and successive generation. Respondents having family history of disability constituted more than a third and female respondents have more family history of disability than male respondents. From here we see that *respondents' family history of disability was significantly high for both males and females*. Among the four categories of generation we also find that history of disability in respondent generation (brother, sister, cousin) was highest.

5.2 Social Support and Persons with Physical Disabilities

The findings show that *from the primary level of support there were few respondents who did not receive any type of support. There were more females than males who fell in this category. Majority of the respondents received emotional support from the primary group and there were more males than females who received emotional support. This was followed by financial support and also accounts for majority out of which there were more female than males. More than half of the respondents also received instrumental support from the primary group. There were more females than males who received this support. Among the supporters in the primary group category, brothers constitute more than a tenth of all the supporters. Among the supporters' mothers and sisters of the respondents also constitutes a little more than a tenth. The rest of the supporters in the primary groups constitute less than a tenth each of all the supporters in the group.*

Almost majority of the respondents did not receive any support from the secondary group. Gender variation can also be seen from the respondents who did not receive support from the secondary groups. The main support given by the secondary group was financial support. Gender variation was present from the support received from secondary groups. Majority of the respondents did not receive support from tertiary groups. The support received by the

respondents from tertiary groups was mainly instrumental support. There is no gender variation.

From the findings, we see that a clear majority did not receive any social support from the three groups put together. There were some respondents who received multiple supports. *In this overall evaluation, social support seemed less because secondary groups and tertiary groups' support were very limited while support from primary groups was found to be strong. Gender variation is not found amongst the support groups.*

5.3 Quality of Life and Persons with Physical Disabilities

The overall perception of the respondents across the domains of Quality of Life is low. Among them, environment domain is found to be most consistent followed by physical health, psychological health and social relationship. Further, we also find that there is few gender differentiation across the domains. There is a correlation among the four dimensions of the Quality of Life of the respondents and each dimension is found to influence the overall Quality of Life. The personal characteristic of the respondents such as age, gender, educational status and monthly personal income is also found to have statistical significance with the Quality of Life domains except the psychological domains.

5.4 Psychosocial Challenges and Persons with Physical Disabilities

The case study clearly shows the societal attitudes towards Persons with Physical Disabilities. They were seen as 'deserving pity', stigmatized and social support from secondary and tertiary levels were less, and they were ignorant from their own rights. However, it was also observed that Persons with Physical Disabilities were willing to work and tried to be self-sufficient from their families and others without depending on others. The important roles that can be played by the church were also seen from the case studies conducted. Barrier free environment was absent in church and other public

settings which handicapped the mobility and participation of Persons with Physical Disabilities.

The findings from the Focus Group Discussion also seem to be similar with the findings from the case studies. Despite their disability they said that they were willing to work for their own living without depending on others. Most of the respondents were engaged in minor occupation with meager monthly income. The meager income could hardly support their needs such as good medical treatment, access of quality aids and appliances etc. Many of the participants perceived their disability was worsening due to poverty and inability to access quality health care. The results show that Persons with Physical Disabilities were stigmatized and discriminated by the society to a large extent in terms of participation in the society as a whole including institutions such as church. Persons with Physical Disabilities were also seems to be interested in sports of which they had no opportunities to let out their craze in different sports discipline. Fair and square distribution of services was insisted so that distributive justice could be obtained. Though Persons with Physical Disabilities were willing to sustain themselves, poverty is still their main setback, at the same time it was difficult for them to avail better health services and they wished for better health insurance. Most of the participants from both the groups indicated that they were mostly timid to participate in social activities. They further pointed out that 'low body image' towards their disability stops them from participation in many social activities. All the participants conclude that though Persons with Physical Disabilities were recognized, respected and looked after by the society, much awareness is still needed to be carried out to help people to have right attitudes towards disability. It was observed that the community response to disability was different according to the community they live in. In some community Persons with Physical Disabilities were given opportunities for participation in different community activities. However, limitation of barrier free environment in public places often limits their participation. The discussion

also reveals that Persons with Physical Disabilities were open to marriage if one can find partners who could accept them as they are. However, the fear of not being able to support their children, the fear of being a burden for other family members hesitate them to get married.

The Key Informants Interviews shows that the implementation of Persons with Disabilities Act in the state was unsatisfactory. Reservation of post for Persons with Physical Disabilities needs concrete and clear cut definitions as Persons with Physical Disabilities were facing challenges with regards to employment. The results also show that Persons with Physical Disabilities themselves were not aware of their rights and dignity. The interview results also show that grassroots organizations functioned effectively within the community and they played as an important agent for the welfare Persons with Physical Disabilities. They become an important source of mediator between Persons with Physical Disabilities and their families, communities and other service providers. However, the interview results also show that the state government is blind with the visibility of these grassroots organization and barely include them in any issues and matters relating to disability at the macro level.

Participatory Rural Appraisal was also conducted through Services and Opportunities map. The result shows that Men with Disability were more aware of their rights and dignity. In other words, they were more aware of the welfare services available for Persons with Disabilities than their female counterparts. Women were observed to be very passive in their response.

5.5 Suggestions

5.5.1 Policy Implications

- i. A gender sensitive approach in providing basic services to Persons with Physical Disabilities must be used in order to fill the gap that exists. In general policies should aim at moving away from a charity

and welfarist approach and instead move towards Rights based approach.

- ii. Initiative to promote human resource on Persons with Physical Disabilities must be promoted. State departments and civil society organizations can play crucial role in this. It is hoped that if human resources among Persons with Physical Disabilities developed, there will be more scope for employment opportunities based upon the capacities of Persons with Physical Disabilities who are also in extreme poverty. Further, the criteria of being a beneficiary for poverty alleviation programmes must include disability. If this is done, the prevalence of unemployment as well as poverty among Persons with Physical Disabilities and their families will decrease.
- iii. Secondary and tertiary support must be strengthened. Grassroots or community based organizations within the community must be equipped with the knowledge and skills of promoting and delivering services for Persons with Physical Disabilities. Similarly, an integrated approach or convergence among government departments must be ensured to deliver services more efficiently. It is hoped that through this, support network will be strengthened and at the same time services will reached the grassroot level.
- iv. Certification programmes must be promoted more in order to reach Persons with Physical Disabilities at the grassroots level. Here, Primary health centers, sub-centers as well as anganwadi centers can be made more responsible in the process of certification.
- v. Extensive training is also needed to be given among Law enforcement officials that include police personnel and Legal personnel. Legal help should also be made affordable and approachable for Persons with Physical Disabilities and they themselves should also be aware of their legal rights which they presently lack.

- vi. Policy formulation process must accommodate the views of Persons with Physical Disability so as to ensure a more inclusive and participatory approach. It is hoped that this will create a more Rights based approach to empower Persons with Physical Disabilities.
- vii. Social model of intervention must be promoted in order to decrease societal barriers. This will reduce handicapped and promote a barrier free environment for Persons with Physical Disabilities. In the line of this suggestion, medical model must go hand in hand with improvement of the social model. In short, it is hoped that integrated approach will helped in strengthening the services for Persons with Physical Disabilities.
- viii. The state must ensure that across its department and jurisdiction, legislations for Persons with Physical Disabilities are implemented effectively. For this to be successful, disability cell can be opened in each state department that will work on the protection and issues relating to disability.
- ix. The state through its various departments can improve capacities, skills and talents of Persons with Physical Disabilities. This will increase scope in the possibility of highlighting the same in local, regional, national and international level.
- x. NGOs forum for Persons with Disability can be mobilized as one strong unifying unit. This will improve networking among the disability community.
- xi. Mechanisms to protect and promote disability rights such as the State Commissioner for Persons with Disabilities can be strengthened by the government. The state must therefore be equipped for these agencies with financial capacity for the smooth functioning of the same to promote and protect disability rights.

5.5.2 Social Work Intervention

- i. Educational institutions must be equipped with resources that will widen the scope of accessibility for Persons with Physical Disabilities in all aspects of learning and skill development. In this respect, there is a need for more sensitization and awareness on the importance of inclusive education among the families of Persons with Physical Disabilities, the community and society as a whole. This will reduce restrictions that arise from the society.
- ii. Interventions to promote parenting skills, relationship skills and communication for Persons with Physical Disabilities and their families can be introduced to promote and strengthen family bond. This will reduce divorce and marital conflicts among PwPDs.
- iii. Since all of the respondents belong to one or the other church and the church being a powerful institution in Mizoram, the same can be used as an agent to promote the rights of Persons with Physical Disabilities in Mizoram. The need to move away from Charity based approaches to Rights based approach is considered important.
- iv. Health services at the grassroots level must be strengthened for early detection and prevention. Besides this, awareness on health must be promoted to sensitize people about the implications of self prescription and superstitions in health care. Further, community based organizations such as YMA, MHIP, MUP and the Church can be used as an arena for promoting health. In other words, community support services in terms of health centers to offer medical and therapy services and home-based care or personal care services should be introduced in order to substitute family support.
- v. Service providers and referral services for Persons with Physical Disability is recommended which is presently limited in Mizoram. The very small number of existing non-governmental organizations should also be given extensive training with regards to disability.

- vi. The facets of the four domains of the Quality of Life such as Physical health, Psychological health, Social relationships and environment can be improved in order to sustain the Quality of Life of Persons with Physical Disabilities through Social Work intervention.
- vii. The physical and emotional capacities of Persons with Physical Disabilities must be respected. This can be ensured through awareness building programmes in the area of disability.
- viii. Counseling and therapeutic services for Persons with Physical Disabilities must be promoted. This can be done through using a *Veng/Khua/Locality* based rehabilitation approach which aims at strengthening the primary, secondary, tertiary levels and capacitating the Persons with Physical Disabilities for developing their skills. This will also ultimately increase their self esteem, confidence, motivation and participation.
- ix. A systemic understanding of society by people working in the area of disability is required in order to improve the situations of Persons with Physical Disabilities. To ensure this, understanding society can be used practically to strengthen social network using the theoretical framework provided by Systems Theory.
- x. The scope of Social Work in the area of disability is promising. Intervention through using different methods such as Working with individuals, Working with groups, Community Organization, Social Work Research, Social Welfare Administration and Social Actions can improve the situations of Persons with Physical Disabilities in Mizoram.
- xi. Media can be used as a means to promote disability rights and protection in Mizoram. It can also act as an important agent to change the societal attitudes towards disability as 'deserving pity'. This can be done by sensitizing media personnel on disability and conducting

various programmes through the media which will ultimately disseminate information to the public.

5.5.3 Research

- i. Social Work research in the area of disability in Mizoram needs to be promoted. Research on Children with Disabilities, Women with Disabilities and different types of disabilities across gender, time and space can be conducted in order to enrich literature on disability in Mizoram.
- ii. From the present study it was seen that Persons with Physical Disabilities had used religion as an important coping strategy. Since in-depth study on coping strategy of Persons with Physical Disabilities is not specifically addressed in the present study, it is suggested as an area for further research.

In conclusion, it was clearly observed that Persons with Disabilities are seen as tragic victims, it follows that they need care, and not capable of managing their own affairs, and need charity in order to survive. At the same time the concept of pity turns out as 'care'. Thus, it led to the growth of *charity*. The idea of being recipients of charity lowers the self-esteem of People with Disability. In the same way, in Mizoram, People with Disabilities were seen by the society and its institution as 'Deserving pity' and this hampers the growth of People with Disabilities. The movement from Charity based approach offered by the church or people in general through welfare towards Rights based approach and Empowerment is very required.

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Appendix 1

SOCIAL SUPPORT AND QUALITY OF LIFE ACROSS GENDER AMONG PERSONS WITH PHYSICAL DISABILITIES IN AIZAWL, MIZORAM

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Interview Schedule (Confidential)

I. Identification Information.

Schedule No.: _____ Date of Interview: _____
Locality: _____ Investigator: _____

II. Profile of the Respondent

a. Name	
b. Age	
c. Gender	1 Male; 2 Female
d. Marital Status	1 Married; 2 Never Married; 3 Divorced; 4 Widowed; 5 Children without marriage
e. Religion	
f. Denomination	
g. Educational Level	0 Illiterate; 1 Kindergarten; 2 Primary; 3 Middle; 4 High School; 5 Higher Secondary; 6 Graduate; 7 PG; 8 Vocational Training School (Specify _____); 9 Others (Specify _____)
h. Type of Family	1 Nuclear family; 2 Joint family; 3 Living alone
i. Form of Family	1 Stable; 2 Broken; 3 Reconstituted
j. Socio-Economic Category	1 APL; 2 BPL; 3 AAY; 4 Annapurna
k. Occupation	
l. Average Monthly Income	
m. Type of disability	
n. Disability certificate	Obtained/not obtained
o. Family history of disability	Yes/No, If yes, who _____ What type of disability _____

III. Family Details

SI no	A	B	C	D	E	F	G
	Relationship with the Respondent	Gender	Age	Marital Status	Highest Educational Level attained	Occupation	Monthly average Income

IV. Social Support

A. Profile of people (primary supporters) who you think are most supportive in times of need

	A	B	C	D	E	F	G	H
SI No.	Name of supporter	Kinds of support given	Relationship with the respondent	Gender	Age	Education	Occupation	Monthly Income

B. Profile of the Secondary and Tertiary Supporters (Government/Organizations) that offer you support

SI No.	Organization	Kinds of support given	Location

Appendix 2

The World Health Organization Quality of Life (WHOQOL)-BREF Translated Version

A hnuaia zawhna hrang hrangte hian i nunphung chungchangte, I hriselna chungchangte leh I nuna thil pawimawh hrang hrangte a rawn zawt dawn che a. Zawhna awmte bakah a chhanna thlan tur hrang hrangte hi ka chhiarchhuah sak vek dawn che a. Tichuan, nangin khawngaih takin nangmah nen a inhmeha I ngaih ber I lo thlang zel dawn nia. Zawhna thenkhatah chhanna thlan tur ber hriat I harsat a nih chuan, I ngaihtuah hmasa ber kha chhanna awm ber a ni fo tih I lo hre dawn nia.

Khawngaihin tlinga I ngaihte, i beisei thin te, nangma tana tha tur duhthusam I neih te leh, I rilru la tute kha reng la. Kar li kalta chhunga I nun hman dan kha han chhui kir la, chumi atang chuan chhan I lo tum dawn nia.

		Tha lo lutuk	Thalo	Pangngai	Tha	Tha lutuk
1	I nun enkawl dan that zawng engtiangin nge i teh ang?	1	2	3	4	5

		Lungawilo lutuk	Lungawilo	Pangai	Lungawi	Lungawi lutuk
2	I hriselna lama I lungawidan	1	2	3	4	5

A hnuaiaw zawnate hi kar li hma lama I thil experience milin chhang tur a ni.

		Engtiang-mahin	Tlema zawngin	Pangngai	Nasa pangaiin	Nasa Lutuk in
3	Engtiang a nasa in nge I taksa na in I thiltihtur a tih thuan awp che?	1	2	3	4	5
4	Nitin pangngai taka khawsa turin damdawia in enkawlna engzatnge I mamawh?	1	2	3	4	5
5	Nun hi engang taka nuam in nge i hman?	1	2	3	4	5
6	Engang chen in nge I nun hian awmzia neitura I duh?	1	2	3	4	5
7	Engtiang a tha in nge I rilru I sawrbing theih?	1	2	3	4	5
8	I nitin nunah him tak leh thlamuang takin i awm thin em?	1	2	3	4	5
9	Nitina I chetna leh I velte hi nangma tan a tha in a hrisel tawk I ti em?	1	2	3	4	5

A hnuaiaw zawnate te hian kar li kalta chhunga tluang taka thil I tih theih dan emaw, harsatna I tawh dante a zawt dawn che a ni.

		Nei lo/Awm lo	Tlemte in	Pangngai	Tha/Nei	Tha/Nei lutuk
10	I nitin nunphung hlen chhuak turin chakna i nei tha tawk em?	1	2	3	4	5
11	I taksa pianphung leh lan dan hi I pawm thei em?	1	2	3	4	5
12	I mamawh puhru turin sum	1	2	3	4	5

	nei tawkin I in hria em?					
13	I nitin mamawh pui tur che in information tha I ban phakah a awm em?	1	2	3	4	5
14	I duhzawng tih nan hun awl I nei thin em?	1	2	3	4	5

		Harsa lutuk	Harsa	Pangngai	Awlsam	Awlsam lutuk
15	I taksa chetkual pui theih dan?	1	2	3	4	5

		Lo lutuk	Aih	A laihaw1	Aw	Lutuk
16	I muhil tha thei em?	1	2	3	4	5
17	I nitin khawsak i hlenchhuah theih dan ah khan i lungawi em?	1	2	3	4	5
18	Hna I thawh theih danah hian I lungawi tawk em?	1	2	3	4	5
19	I nihna leh I awmdan ah hian I lungawi tawk em?	1	2	3	4	5
20	Midang nena in inkungkaihna ah I lungawi tawk em?	1	2	3	4	5
21	Hmeichhiat-mipatna hmankawngah I lungawi em?	1	2	3	4	5
22	I thiante atanga tanpuina I dawnah I lungawi tawk em?	1	2	3	4	5
23	Tuna I chenna hmun ah te hian I lungawi tawk em?	1	2	3	4	5

24	I in enkawl nan damdawiin emaw inenkawl nate pan zung zung theih in a awm em. Tin, enkawl nate chu a tha tawk I ti em?	1	2	3	4	5
25	I chetvelna atan transportation a awlsam tawk I ti em?	1	2	3	4	5

A hnuai a zawhna te hi kar li hma lama I thil tawnhriat milin chhang tur a ni.

		Nei Ngai miahlo	Nei Ngai vak lo	Nei zeuhzeuh	Nei ve fo	Nei reng
26	Rilru hnualnate, lungawilonate, hlauhna leh beisei bona leh nun in awmzia awmlo tih chhang engtianga nasa/zing in nge I neih thin?	1	2	3	4	5

A chung a mite bakah khian belh duh neih I nei em?

Appendix 3

WHOQOL-BREF

The following questions ask how you feel about your Quality of Life, health, or other areas of your life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

1.	How would you rate your Quality of Life?	Very poor	Poor	Neither poor nor good	Good	Very good
		1	2	3	4	5

2.	How satisfied are you with your health?	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
		1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

15.	How well are you able to get around?	Very poor	Poor	Neither poor nor good	Good	Very good
		1	2	3	4	5

		Satisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

Do you have any comments about the assessment?

Appendix 4

Serial No:

Interview Guide for Focus Group Discussion

Social Support and Quality of Life across Gender Among Persons with Physical Disabilities in Aizawl, Mizoram

Research Scholar
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Research Supervisor
Dr.KalpanaSarathy
Associate Professor
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Mizoram University

I, _____ agree to participate and share my experiences in this focus group discussion for the cause of disability.

I. Interview guide for First and Second Focus Group Discussions

A. Economic Participation

- a. At the primary level
- b. At the secondary level
- c. At the tertiary level

B. Social Participation

- a. Family level
- b. Marriage
- c. Church
- d. Community
- e. Others

C. Education

- a. services and opportunities etc

D. Personal response when first acquired disability

- a. First response
- b. Coping
- c. As a whole, their experience of disability, change of identity

E. Causes of disability (perception)

F. Suggestions

II. Guide for the third Focus Group Discussion

Issues and Challenges faced by PwPDs in terms of Marriage-

- a. Advantage of Marriage for Persons with Physical Disability
- b. Disadvantage of Marriage for Persons with Physical Disability
- c. Divorce from the lens of Persons with Physical Disability
- d. Parenting from the lens of Persons with Physical Disability

III. The KI Interview guide consists of the following key questions-

- a. Implementation of the Mizoram Persons with Disabilities (Equal opportunities, Protection of Rights and Full participation) Rules 1999.
- b. Challenges faced by Persons with Physical Disabilities at the levels of Micro, Mezzo and Macro
- c. Support systems and services for Persons with Physical Disability
- d. Suggestions and Recommendations

Appendix 5

Tables

Table 12. List of Participants: Focus Group Discussion from the Urban Core

Sl No.	Name	Type of disability	Age	Gender	Marital Status	Educational Qualification	Occupation	Monthly income
1.	Atea	VI	36	Male	Unmarried	High School	Unemployed	-
2.	Beisei	HI	27	Male	Unmarried	Middle School	Part time job	Rs 3000/-
3.	Chawnga	Locomotor	23	Male	Unmarried	Graduate	Business	Rs.3000/-
4.	Dawnga	Locomotor	35	Male	Unmarried	Graduate	Private Firm employee	Rs. 8000/-
5.	Engi	HI	42	Female	Widowed	High School	Knitting	Rs. 5000/-
6.	Rovi	Locomotor	20	Female	Unmarried	High School	Unemployed	-
7.	Mawii	Locomotor	50	Female	Unmarried	Primary(not completed)	Unemployed	-
8.	Hrili	Locomotor	37	Female	Married	Middle School	Petty Business	Rs. 3000/-

Table 13. List of Participants: Focus Group Discussion from Urban Periphery

Sl No.	Name	Type of disability	Age	Gender	Marital Status	Educational Qualification	Occupation	Monthly income
1.	Sanga	HI	53	Male	Married	Middle School (not completed)	Carpenter	Rs. 8000/-
2.	Zawna	Locomotor	24	Male	Unmarried	Middle School (not completed)	Unemployed	-
3.	Kimi	HI	54	Female	Widow	Illiterate	Vegetable seller	Rs 5000/-
4.	Liana	VI	52	Male	Married	High School	Butcher	Rs.6000/-
5.	Thangi	Multiple Disability (VI & HI)	62	Female	Widow	Illiterate	Agricultural work	Rs.2000/-
6.	Nupuii	HI	78	Female	Widow	Illiterate	Unemployed	-
7.	Thana	HI	80	Male	Widowed	Illiterate	Unemployed	-
8.	Pari	Locomotor	21	Female	Unmarried	Class IX	Unemployed	-
9.	Rini	HI	18	Female	Unmarried	Class XII	Unemployed	-
10.	Sawma	VI	57	Male	Widowed	Class III	Poultry farming	Rs. 2000/-

Table 14. List of Participants: Participatory Rural Appraisal

SI No.	Name	Type of disability	Age	Gender	Marital Status	Educational Qualification	Occupation	Monthly income
1.	Beisei	HI	27	Male	Unmarried	Middle School	Part time job	Rs 3000/-
2.	Rovi	Locomotor	20	Female	Unmarried	High School	Unemployed	-
3.	Kimi	HI	54	Female	Widow	Illiterate	Vegetable seller	Rs 5000/-
4.	Pari	Locomotor	21	Female	Unmarried	Class IX	Unemployed	-
5.	Dawnga	Locomotor	35	Male	Unmarried	Graduate	Private Firm employee	Rs. 8000/-
6.	Liana	VI	52	Male	Married	High School	Butcher	Rs.6000/-
7.	Sawma	VI	57	Male	Widowed	Class III	Poultry farming	Rs. 2000/-
8.	Zawna	Locomotor	24	Male	Unmarried	Middle School (not completed)	Unemployed	-
9.	Chawnga	Locomotor	23	Male	Unmarried	Graduate	Business	Rs.3000/-

Table 15. List of participants of Key Informants Interview

Sl No.	Key Informants Interview	Date of interviewed	Number of persons	Duration
1.	Social/Human rights activist	12.09.2011 & 3.12.2013	1(female)	2 hours
2.	Disability rights activist	26.09.2013 & 17.05.2014	1(male)	2.5hours
3.	Church leader (two persons from two localities)	12.06. 2014	2 (male)	2hours
4.	Community leaders			
	(1) NGOs (MUP, MHIP, YMA)	21. 07. 2014	3 (2 male, 1 female)	1.5 hours
	(2) Local Council Members (two persons from two localities)	22. 07. 2014	2 (male)	1.5 hours
5.	Government officials			
	(1) Nodal Officer for Persons with Disability	27.08.2013 & 22.10.2014	1(male)	1 hour
	(2) District Social Welfare Officer (Social Welfare Department)	27.08.2011 & 22.10.2014	1(male)	1.5 hours
	(3) Research cum Assistant (Office of the Commissioner for Persons with disability)	10.04.2014 & 09. 05. 2014	1(female)	1 hour
	(4) Dealing Assistant for Persons with disability (Social Welfare Department)	30.06.2013 & 21. 08. 2014	2(female)	2.5hours
6.	CBR Project coordinators and field workers			

	1. ZoramEntu Pawl	12.11.2013	2 (1 male, 1 female)	45 minutes
	2. MZU, NIOH	13.11.2013 & 29.08.2014	1 (male)	1.5 hours
	3. Center for Peace and Development	15.11.2013	1 (female)	45 minutes
	4. Presbyterian Durtlang Hospital	3.09.2014	1 (male)	45 minutes
	5. FIWDC, Durtlang	29.11.2013	1 (female)	45 minutes
7.	President and Secretary, Disabled Peoples Organization, Tlangnuam Block	12.09.2011 & 17.05.2014	2 (2 males)	2.5hours

**SOCIAL SUPPORT AND QUALITY OF LIFE ACROSS GENDER AMONG PERSONS
WITH PHYSICAL DISABILITIES IN AIZAWL, MIZORAM**

ABSTRACT

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1. Introduction

The study explores the Quality of Life and Social Support of Persons with Physical Disabilities (PwPDs). It seeks to profile Persons with Physical Disability, examine their psycho-social challenges, understand the Quality of Life across gender, assess their social support and suggest measures for policy making and for social work intervention.

People with Disabilities are the world's largest minority, yet "Persons with Disabilities have to face problems not only because of their handicap but also due to non-addressal of their socio-emotional needs" (Singh, Sharma, Chandra, Nigam & Verma, 2011, p. 20).

The Disabled People's Movement during 1970s' led to the development of disability studies as an academic discipline (Oliver & Barnes, 2010). The emergence of social model of disability led to the understanding of disability as social oppression and this came connected with disability rights, social justice and human rights and therefore disability studies gradually emerged as an important studies in higher education (as cited in Oliver & Barnes, 2010). However, in many cases they were excluded from developmental plans and policies. The Quality of Life of PwDs varies, however they have poorer QoL as compared to those who are not. Therefore, to have a better understanding of the current situation of Persons with Disabilities research based findings are needed to be carried out for improving the life of Persons with Physical Disabilities.

1.1. Global Perspective on Persons with Disabilities

As far as history is concerned, mention of Persons with Disabilities can be traced back to the medieval period. Records suggest that during this period, people were helping the poor including Persons with Disabilities more out of a religious obligation. The Medical Model of Disability began to have its deep root in disability and disability is seen as a malfunction in one's body that has to be treated or corrected. The medical model lays emphasis on individual

impairments and classifications systems (Fawcett, Featherstone, Fook, & Rossiter, 2000).

During the 20th Century, Rights based approach towards the care and rehabilitation of Persons with Disabilities was introduced as a result of international conventions and agreements. *The Convention recognized 'the diversity of Persons with Disabilities, the need to promote and protect the human rights of all Persons with Disabilities, including those who require more intensive support'*.

At present, around 15 per cent of the world's population, or an estimated 1 billion people, live with disabilities. This figure is increasing through population growth; medical advances and the ageing process. About 15 out of every 100 people in the world have a disability (WHO, 2011). "The overall low levels of development and inadequate health and social welfare services have all contributed to the persistence of poor Quality of Life among the disabled people in these countries" (Hosain, Atkinson & Underwood, 2002, p. 297). This study refers to global, national, local perspectives on disability.

1.2. National Perspective on Persons with Disabilities

The response to disability in India can be traced back from the ancient period. The services given for Persons with Disability have been documented. India has also laid down several legislations for the welfare of Persons with Disabilities. She is home to the largest population of Persons with Disability in the world next to China (Klasing, 2007). The number of Persons with Disabilities which was 2.19 crore in 2001, rose in 2011 to 2.68 crore (1.5 crore males and 1.18 crore females). Rural areas have more Persons with Disability than urban areas. Therefore, the magnitude and scope of research is illustrated.

1.3 Local Perspective on Persons with Disabilities

Mizoram is a storehouse of natural beauty; it occupies an importance strategic position having a long international boundary of 722 Kms bordered by Bangladesh on the west and Myanmar on the east and south. It is a land of rolling hills, rivers and lakes. As many as 21 major hills ranges or peaks of different heights run through the length and breadth of the state. The terrain has the most variegated topography among all hilly areas in this part of the country. The hills are extremely rugged and steep and the ranges and leaving some plains scattered (GoM, 2015). The state of Mizoram has eight districts and among which Aizawl district has the highest population.

The fabric of social life in the Mizo society has undergone tremendous changes over years. Before the British moved into the hills, for all practical purposes the village and the clan formed units of Mizo society. The Mizo code of ethics or Dharma moved around ‘Tlawmngaihna’, meaning everyone to be hospitable, kind, unselfish and helpful to others. The Mizos have been enchanted to their new-found faith of Christianity with so much dedication and submission that their entire social life and thought-process been transformed and guided by the Christian Church Organisation and their sense of values has also undergone drastic change. The Mizos are a close-knit society with no class distinction (GoM, 2015).

The government of Mizoram passed legislation for the welfare of Persons with Disability in Mizoram. In the exercise of powers conferred under section 73 (1) of The Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Act, 1995 (1 of 1996), the governor of Mizoram notified ‘The Mizoram Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Rules, 1999’. Persons with Disability Rules in Mizoram cover the welfare of Persons with Disabilities from reservation in Government job, creation for the office of the Commissioner for Persons with Disabilities and Certification Camp etc.

According to Vanramchhuangi (2013), the status of Persons with Disabilities in Mizoram is fair however there is still a long way to go for developing the welfare of PwDs in Mizoram.

In Mizoram there are 15,160 Persons with Disability. In this, Persons with Visual impairment comprises the highest percentage, followed by Persons with Multiple disabilities, Persons with Visual impairment, Persons with Locomotor disability, Persons with Mental retardation, Persons with Speech impairment and Persons with Mental illness (Census Reports, GoI, 2011).

1.4 Definitions and Concepts

The term *Disability* has a variety of connotations that can be interpreted differently (Fairchild, 2002). “A disability may be physical, cognitive, mental, sensory, emotional, and developmental or some combination of these. In simple term, disability is defined as ‘any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being’ (Romney, Brown, Fry, 1994 & Metts, 2000).

“*Social support* has been conceptualized in many different ways as it is a multidimensional concept” (as cited in Huurre, 2000, p. 20). “Social support consists of social relationships that provide or can potentially provide material and interpersonal resources that are of value to the recipient (as cited in Miyahara, 2008, p.14). Huurre (2000) also cited that “Social support can be divided into primary level, secondary level and tertiary level on the basis of the intimacy of social relationships. The *primary level* support structure includes one’s own family and closest friends. The *secondary level* includes friends, relatives, workmates and neighbours and the *tertiary level* the authorities and other distant support structure. Social Support may be given by professionals and non-professionals” (as cited in Huurre, 2000, p.21). Studies also distinguish four types of support such as *emotional support* (trust,

empathy and love), *instrumental support* (helping behaviours such as giving one's time and skill), *informational support* (advice) and *appraisal support* (evaluative feedback). Thus, in order to give Persons with Disabilities opportunities for inclusion in all dimensions of their life, investigating the individuals' perception on their social world and the type of support they received is needed. (Alotaibi, 1997).

Schippers (2010) cites several authors to discuss *Quality of Life*. "Quality of Life (QoL) is an integrating concept, which takes into account a holistic concept. The domains of QoL also cover all areas from health, finance, community, family, employment and education" (p. 279 & 280). The World Health Organization defines Quality of Life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (as cited in Chandra & Ozturk, 2005, p. 33). It is a broad and complex concept which incorporates physical health, psychological state, and level of independence, social relationships, personal beliefs, and relationship to salient features of the environment.

Physical Disability generally refers to "impairment that interferes with an individual's mobility, co-ordination, and communication, learning or personal adjustment. In other words, Physical disorders frequently interfere with person's capacity to speak to others, to move about independently, to engage in various activities and to develop certain academic and social skills" (Greenglass, Fiksenbaum, Eaton, 2006, & Mjelde-Mossey, 2006).

The discourse of *gender* in relation to Persons with Disability is often ignored. Connell explained that "Gender is the structure of social relations that centers on the reproductive arena, and the sets of practices (governed by this structure) that bring reproductive distinctions between bodies into social processes" (as cited in Meekosha, 2004).

1.5 Operational Definitions

For this study, *Persons with Physical Disability* includes persons over the age of 18 years across gender residing within Aizawl District and having one or more defects in vision, speech, hearing and locomotor disability.

Social Support includes Emotional, Financial and Instrumental support by Primary Supporters (Family, Close Relatives and Friends), Secondary Supporters (CBOs, NGOs and Private agencies) and Tertiary Supporters (Government). Instrumental Support involves the provision of tangible assistance, in the form of material goods, labor, time, or any direct help. Emotional Support involves the provision of empathy, affection, love, trust, encouragement, listening, and cares from members of an individuals' social network. Financial Support involves financial aid.

There are no definitions and clear concepts of the challenges faced by PwPDs. It is solely dependent on the perceived challenges faced by the respondents during qualitative method of data collection (Case vignettes, Focus Group Discussion, Participatory Approach and Key Informant Interviews).

1.6 Statement of the Problem

The slow progress in expanding opportunities for disabled people in India results in substantial losses to People with Disabilities themselves. The international year of disabled persons was even declared in 1976. However, despite the laws, legislations, programmes and services lay down; People with Disability continue looking for opportunities to deal with their challenges as normal persons in the society. Persons with Disability themselves remain largely outside the policy and implementation framework (World Bank, 2011). In Mizoram the situation is not much better; there are many Persons with Disabilities who are still waiting for access, opportunities and changes in structure so that there is better inclusiveness. Lack of adequate and satisfactory

social support for Persons with Disability would hamper the Quality of Life in terms of emotional, physical and social wellbeing lived by them.

Better inclusiveness and an enabling environment would result in an enhanced Quality of Life for the Persons with Disability. *Although it would be important to understand the Quality of Life of Persons with Disability in Mizoram, given the context of social life and particulars of the physical and geographical terrain in Mizoram, this study focuses on the challenges faced by Persons with Physical Disabilities in particular.* It is with these objectives that this study explores the levels of Quality of Life and social support among the Persons with Physical Disabilities in Mizoram.

1.7 Objectives

1. To profile Persons with Physical Disability (PwPDs) in Mizoram.
2. To assess the Social Support of Persons with Physical Disability at the primary, secondary and tertiary levels.
3. To understand the Quality of Life of Persons with Physical Disability.
4. To examine the psycho-social challenges of Persons with Physical Disability.
5. To suggest measures for policy making and for social work intervention.

1.8 Chapter Scheme

Chapter 1	Introduction
Chapter 2	Review of Literature
Chapter 3	Methodology
Chapter 4	Results and Discussion
Chapter 5	Conclusion and Suggestion

2. Review of literature

There is copious literature related to disability issues, and the selected literature in this study focus on Quality of Life, Social Support of Persons with Physical Disability, Psycho-social challenges, and Inclusiveness of disability as a whole. Review of literature helped in identifying substantive, theoretical, methodological, conceptual issues and addresses them in the context of the present study.

The literature reviewed throws light on the importance of the demographic and economic characteristics of Person's with Physically Disability. The studies assessed the Social Support and Quality of Life of Persons with Disabilities to highlight level of life satisfaction, coping strategies, and psycho social challenges among Persons with Disabilities. The review of local literature also helped in gaining insights on the position of Persons with Disabilities in Mizoram.

3. Methodology

3.1. Profile of the study area

The present study was conducted within Aizawl City, the capital of Mizoram, in 17 urban localities of Tlangnuam RD Block. Aizawl is one of the 8 Districts of Mizoram. According to 2011 Census, the population of Aizawl District is 4, 040, 54. It is the highest population among the eight Districts of Mizoram. Aizawl has a mild, subtropical climate due to its location and elevation (GoM, 2011).

3.2 Research design

The study is cross-sectional in nature and exploratory in design. The study is based on primary data collected through quantitative and qualitative methods by using a semi-structured interview schedule among adult respondents of Persons with Physical Disability who were above 18 years of age. Secondary data from government and non-government sources were also

collected. Persons with Physical Disability in this study included all persons above the age of 18 years with Visual impairment, Hearing impairment, Speech impairment and Locomotor disability residing in Aizawl district. A participatory method such as Services and Opportunities map was used to understand the context of the persons with disabilities.

3.3 Sampling

A multi-stage sampling procedure was used for selection of the *Veng/Khua/Locality* and the respondents. In the first stage, within Aizawl District, the Block i.e. Tlangnuam Block which has the highest population of PwDs was selected. In the second stage, secondary data on the number of PwDs in 70 *Veng/Khua/Locality* within Tlangnuam Block was collected which included 976 PwDs (Source: CBR Project, NIOH & MZU, 2009-2011). In the next stage, PwDs from each *Veng/Khua/Locality* were screened for eligibility and filtered in order to meet the operational definition of the study. As such the number came down to 55 and the population of PwDs came down to 387. *The total sample size was 196 (116 male and 80 female)*. The sample size for the present study is calculated by referring to Morgan & Krejcie (1970). In the fourth stage, the 55 *Veng/Khua/Locality* were divided into Core and Peripheral ones based on their vicinity (15 km approx.) from the center of Aizawl City i.e. Treasury Square, Aizawl. There were 34 Core *Veng/Khua/Locality* and 21 Peripheral *Veng/Khua/Locality*. *In the fifth stage, 11 Veng/Khua/Locality from the Core category and 6 Veng/Khua/Locality from the Peripheral category were selected taking into consideration the gender population, distribution and proportion of Persons with Disabilities in each Veng/Khua/Locality. The Veng/Khua/Locality representing the Core category were Ramthar Veng, Chanmari West, Electric Veng, Venghnuai, Ramhlun Vengthar, Chhinga Veng, Thakthing, Ramhlun Venglai, Vaivakawn, Tlangnuam, Electric Veng. The Veng/Khua/Locality representing the Peripheral category include Tuivamit, Tanhril, Sairang, Maubawk, Zemabawk and Sihphir. All in all, there*

were 109 (72 male and 37 female) respondents representing the Core Veng/Khua/Locality and 87 (44 Male and 43 Female) representing the Peripheral Veng/Khua/Locality as a final sample. All Persons with Physical Disabilities who fulfilled the age criteria and fall within the selected sample areas and who had given their consent were included in the survey.

3.4 Tools of Data Collection

A semi-structured interview Schedule was used for obtaining information from Persons with Physical Disability on demographic details and social support. A guide for Focus Group Discussions was prepared to collect information on the perceived challenges and coping mechanisms across gender in respect to disability. Key Informant Interviews were conducted from disability activists, church leaders, community leaders, CBR Project workers and field workers, DPO member and government personnel to obtain information on services and programmes as well as on advocacy issues. Seven Case vignettes were compiled to document the Quality of Life and psycho social challenges of men and women with Physical Disabilities. PRA technique of Services and Opportunities map was also administered. The WHOQoL BREF tool was used to measure the Quality of Life of Persons with Physical Disabilities.

The WHOQoL-BREF contains a total of 26 questions. To provide a broad and comprehensive assessment, one item from each of the 24 facets contained in the WHOQoL-100 has been included. In addition, two items from the Overall quality of Life and General Health facet have been included. WHOQoL BREF version comprises of four domains such as physical health, psychological health, social relationships, and environment". All items are rated on a five point scale (WHO, 2004).

Focus Group Discussion was conducted with Persons with Physical Disabilities from the urban core. The first group had eight participants, four participants each from both the gender. Differently Abled Society (DAS) was

contacted for selecting the participants. The age of respondents was ranged between 20 to 50 years (see table 15). The second Focus Group Discussion was held among Persons with Physical Disabilities in the urban periphery. There were ten participants, five participants each from both male and female. Disabled People's Organization (DPO) under CBR Project was contact for selecting the participants. Their age ranged between 18 to 80 years (see table 16). The third group FGD was conducted Focus Group Discussion among People with Physical Disability was conducted in order to understand the issues and challenges of marriage faced by Persons with Physical Disability. There were nine participants, five of them were males and the other four participants were females.

Services and Opportunities mapping was conducted among men and women with Physical Disabilities separately from the urban core and urban periphery. Male participants of the urban core and urban periphery assemble in one place and female participants of the urban core and urban periphery at another place. There were nine participants (males=5 and female=4) across the Veng/Khua/Locality.

3.5 Data Processing and Analysis

The quantitative data collected through interview schedule was processed with the help of computer packages of Microsoft Excel, and SPSS package. To analyze the data, frequency, cross tabulation, averages and proportionate percentages was used. Karl Pearson's coefficient of correlation was also used. Data collected from focus group discussion and PRA exercises was analyzed and are presented in a summative form. Case vignettes are also presented with discussion.

3.6 Limitations of research

The research does not adequately represent the perceptions of the respondents because for hearing impaired and speech impaired the researchers

had to rely on the care givers, parents or family members to interpret responses. A further limitation is that since many respondents were mostly not alone in the house while interviewing, it was observed that the respondents were hesitant to share their views and perception. Though much effort had been taken, collection of quality data required time on the part of the researcher, trust on the part of respondents was not easy to build with such a short period of time.

4. Major findings of the present study

The major findings of the study are discussed in relation to the objectives of the present study in terms of the socio-demographic profile of the respondents, their social support, Quality of Life and psycho-social challenges.

4.1 Profile of Persons with Physical Disabilities

- i) The mean age of the respondents was 46.3 years. There was no significant difference in the mean age across gender. Overall, the respondents were in their middle age.
- ii) Almost half of the respondents were never married. A tenth of the respondents were however divorced and here there were more females than males. Almost a tenth of the respondents were also widowed.
- iii) Nearly a fourth of the respondents were illiterate and there were more illiterate females than males.
- iv) Majority of the respondents were from a stable family. In this category there were more males than females
- v) The mean size of family was 4.2 members. Half of the respondents were from medium size family. There were more females than males who lived in this category.
- vi) Respondents belonging to the Presbyterian denomination constituted more than half of the sample size.

- vii) The findings revealed that more than half of the studied population was unemployed. In this category there were more unemployed female respondents than males.
- viii) Nearly half of the respondents were from poor socio-economic background. In this category there were more females than males.
- ix) The findings of the present study also show that the mean monthly income of the respondents was Rs **2332.5**. Gender variation can be seen, male respondents earn more monthly income than female respondents.
- x) Almost half of the respondents were hearing impaired. This category was followed by respondents have locomotor disability, speech impaired and visually impaired.
- xi) The present findings also reports that less than half of the respondents were reported as possessing disability certificate out of which there were more females than males who possessed disability certificate.
- xii) The family history of disability was categorized into grand parents' generation, parents' generation, respondents' generation and successive generation. Respondents having family history of disability constituted more than a third and female respondents have more family history of disability than male respondents.

4.2 Social Support and Persons with Physical Disabilities

- i) The findings show that from the primary level there were few respondents who did not receive any type of support. There were more females than males who fell in this category. Majority of the respondents received emotional support from the primary level and there were more males than females who received emotional support. This was followed by financial support and also accounts for majority out of which there were more females than males. More than half of

- the respondents also received instrumental support from the primary level. There were more females than males who received this support.
- ii) Almost majority of the respondents did not receive any support from the secondary level. There is no gender variation.
 - iii) Majority of the respondents did not receive support from tertiary level. The support received by the respondents from tertiary level was mainly instrumental support. There is no gender variation.
 - iv) From the findings, we see that a clear majority did not receive any social support from the three levels of support put together. There were some respondents who received multiple supports. In this overall evaluation, social support seemed less because secondary level and tertiary level of supports were very limited while support from primary level was found to be strong. Gender variation is not found amongst the support levels.

4.3 Quality of Life and Persons with Physical Disabilities

- i. The overall perception of the respondents across the domains of Quality of Life is low. Among them, environmental domain is found to be most consistent followed by physical health, psychological health and social relationship. Further, we also find that there is very few gender differentiation across the domains.
- ii. There is a correlation among the four dimensions of the Quality of Life of the respondents and each dimension is found to influence the overall Quality of Life.
- iii. The personal characteristic of the respondents such as age, gender, educational status and monthly personal income is also found to have statistical significance with the Quality of Life domains except the psychological domains.

4.4 Psycho Social Challenges and Person with Physical Disabilities

- i. The case vignettes clearly shows the societal attitudes towards Persons with Physical Disabilities. They were seen as ‘deserving pity’, stigmatized and social support from secondary and tertiary levels were less, and they were ignorant from their own rights. However, it was also observed that Persons with Physical Disabilities were willing to work and tried to be self-sufficient from their families and others without depending on others. The important roles that can be played by the church were also seen from the case vignettes conducted. Barrier free environment was limited in church and other public settings which handicapped the mobility and participation of Persons with Physical Disabilities.
- ii. The findings from the Focus Group Discussion also seem to be similar with the findings from the case vignettes. Despite their disability PwPDs were willing to work for their own living without depending on others. Most of the respondents were engaged in minor occupation with meager monthly income. The meager income could hardly support their needs such as good medical treatment, quality aids and appliances etc. Many of the participants perceived their disability was worsening due to poverty and inability to access quality health care. The results also show that Persons with Physical Disabilities were stigmatized and discriminated by the society to a large extent in terms of participation in the society as a whole including institutions such as the church. Persons with Physical Disabilities were also interested in sports for which they had less opportunity. Fair and square distribution of services was insisted so that distributive justice could be obtained. Though Persons with Physical Disabilities were willing to sustain themselves, poverty is still their main setback, at the same time it was difficult for them to avail better health

services and they wished for better health insurance. Most of the participants from the groups indicated that they were mostly hesitant to participate in social activities. They further pointed out that 'low body image' prevents them from participation in many social activities. All the participants conclude that though Persons with Physical Disabilities were to a great extent accepted and looked after by the society, much awareness is still needed to be carried out to help people to have right attitudes towards disability. It was observed that the community response to disability was different according to the community they live in. In some areas Persons with Physical Disabilities were given opportunities for participation in different community activities. However, limitation of barrier free environment in public places often limited their participation.

The results of FGD also reveal that PwPDs were open to marriage. However, the fear of not being able to support their children, fear of being a burden to other family members made them reluctant and hesitant to get married.

- iii. The Key Informants Interview shows that the implementation of Persons with Disabilities Act in the state was unsatisfactory. Reservation of post for Persons with Physical Disabilities needs concrete and clear cut definitions as Persons with Physical Disabilities were facing challenges with regards to employment. The results also show that Persons with Physical Disabilities themselves were not aware of their rights and dignity. The interview results also show that grassroots organizations functioned effectively within the community and they played an important agent for the welfare Persons with Physical Disabilities. They become an important source of mediator between Persons with Physical Disabilities and their families, community and other

service providers. However, the interview results also show that the state government is not drawing on the rich experience of grassroots organizations and barely consults or includes them in issues and matters relating to disability at the macro level.

- iv. Participatory Rural Appraisal was also conducted through the use of techniques such as Services and Opportunities map. The results show that Men with Disability were more aware of their rights and dignity. In other words, they were more aware of the welfare services available for Persons with Disabilities than their female counterparts. Women were observed to be very passive in their response.

5. Suggestions

5.1 Policy Implications

- i. A gender sensitive approach in providing basic services to Persons with Physical Disabilities must be used in order to fill the gap that exists. In general policies should aim at moving away from a charity and welfarist approach and instead move towards Rights based approach.
- ii. Initiative to promote human resource on Persons with Physical Disabilities must be promoted. State departments and civil society organizations can play crucial role in this. It is hoped that if human resources among Persons with Physical Disabilities developed, there will be more scope for employment opportunities based upon the capacities of Persons with Physical Disabilities who are also in extreme poverty. Further, the criteria of being a beneficiary for poverty alleviation programmes must include disability. If this is done, the prevalence of unemployment as well as poverty among Persons with Physical Disabilities and their families will decrease.

- iii. Secondary and tertiary support must be strengthened. Grassroots or community based organizations within the community must be equipped with the knowledge and skills of promoting and delivering services for Persons with Physical Disabilities. Similarly, an integrated approach or convergence among government departments must be ensured to deliver services more efficiently. It is hoped that through this, support network will be strengthened and at the same time services will be reached the grassroots level.
- iv. Certification programmes must be promoted more in order to reach Persons with Physical Disabilities at the grassroots level. Here, Primary health centers, sub-centers as well as anganwadi centers can be made more responsible in the process of certification.
- v. Extensive training is also needed to be given among Law enforcement officials that include police personnel and Legal personnel. Legal help should also be made affordable and approachable for Persons with Physical Disabilities and they themselves should also be aware of their legal rights which they presently lack.
- vi. Policy formulation process must accommodate the views of Persons with Physical Disability so as to ensure a more inclusive and participatory approach. It is hoped that this will create a more Rights based approach to empower Persons with Physical Disabilities.
- vii. Social model of intervention must be promoted in order to decrease societal barriers. This will reduce handicapped and promote a barrier free environment for Persons with Physical Disabilities. In the line of this suggestion, medical model must go hand in hand with improvement of the social model. In short, it is hoped that integrated approach will help in strengthening the services for Persons with Physical Disabilities.
- viii. The state must ensure that across its department and jurisdiction, legislations for Persons with Physical Disabilities are implemented

effectively. For this to be successful, disability cell can be opened in each state department that will work on the protection and issues relating to disability.

- ix. The state through its various departments can improve capacities, skills and talents of Persons with Physical Disabilities. This will increase scope in the possibility of highlighting the same in local, regional, national and international level.
- x. NGOs forum for Persons with Disability can be mobilized as one strong unifying unit. This will improve networking among the disability community.
- xi. Mechanisms to protect and promote disability rights such as the State Commissioner for Persons with Disabilities can be strengthened by the government. The state must therefore be equipped for these agencies with financial capacity for the smooth functioning of the same to promote and protect disability rights.

5.2 Social Work Intervention

- i. Educational institutions must be equipped with resources that will widen the scope of accessibility for Persons with Physical Disabilities in all aspects of learning and skill development. In this respect, there is a need for more sensitization and awareness on the importance of inclusive education among the families of Persons with Physical Disabilities, the community and society as a whole. This will reduce restrictions that arise from the society.
- ii. Interventions to promote parenting skills, relationship skills and communication for Persons with Physical Disabilities and their families can be introduced to promote and strengthen family bond. This will reduce divorce and marital conflicts among PwPDs.
- iii. Since all of the respondents belong to one or the other church and the church being a powerful institution in Mizoram, the same can be used

an agent to promote the rights of Persons with Physical Disabilities in Mizoram. The need to move away from Charity based approaches to Rights based approach is considered important.

- iv. Health services at the grassroots level must be strengthened for early detection and prevention. Besides this, awareness on health must be promoted to sensitize people about the implications of self prescription and superstitions in health care. Further, community based organizations such as YMA, MHIP, MUP and the Church can be used as an arena for promoting health. In other words, community support services in terms of health centers to offer medical and therapy services and home-based care or personal care services should be introduced in order to substitute family support.
- v. Service providers and referral services for Persons with Physical Disability is recommended which is presently limited in Mizoram. The very small number of existing non-governmental organizations should also be given extensive training with regards to disability.
- vi. The facets of the four domains of the Quality of Life such as Physical health, Psychological health, Social relationships and environment can be improved in order to sustain the Quality of Life of Persons with Physical Disabilities through Social Work intervention.
- vii. The physical and emotional capacities of Persons with Physical Disabilities must be respected. This can be ensured through awareness building programmes in the area of disability.
- viii. Counseling and therapeutic services for Persons with Physical Disabilities must be promoted. This can be done through using a *Veng/Khua/Locality* based rehabilitation approach which aims at strengthening the primary, secondary, tertiary levels and capacitating the Persons with Physical Disabilities for developing their skills. This will also ultimately increase their self esteem, confidence, motivation and participation.

- ix. A systemic understanding of society by people working in the area of disability is required in order to improve the situations of Persons with Physical Disabilities. To ensure this, understanding society can be used practically to strengthen social network using the theoretical framework provided by Systems Theory.
- x. The scope of Social Work in the area of disability is promising. Intervention through using different methods such as Working with individuals, Working with groups, Community Organization, Social Work Research, Social Welfare Administration and Social Actions can improve the situations of Persons with Physical Disabilities in Mizoram.
- xi. Media can be used as a means to promote disability rights and protection in Mizoram. It can also act as an important agent to change the societal attitudes towards disability as 'deserving pity'. This can be done by sensitizing media personnel on disability and conducting various programmes through the media which will ultimately disseminate information to the public.

5.3 Research

- i. Social Work research in the area of disability in Mizoram needs to be promoted. Research on Children with Disabilities, Women with Disabilities and different types of disabilities across gender, time and space can be conducted in order to enrich literature on disability in Mizoram.
- ii. From the present study it was seen that Persons with Physical Disabilities had used religion as an important coping strategy. Since in-depth study on coping strategy of Persons with Physical Disabilities is not specifically addressed in the present study, it is suggested as an area for further research.

In conclusion, it was clearly observed that Persons with Disabilities are seen as tragic victims, it follows that they need care, and not capable of managing their own affairs, and need charity in order to survive. At the same time the concept of pity turns out as 'care'. Thus, it led to the growth of *charity*. The idea of being recipients of charity lowers the self-esteem of People with Disability. In the same way, in Mizoram, People with Disabilities were seen by the society and its institution as 'Deserving pity' and this hampers the growth of People with Disabilities. The movement from Charity based approach offered by the church or people in general through welfare towards Rights based approach and Empowerment is very required.