Rehabilitation of Disabled and Inclusive Development: A Study in Aizawl District of Mizoram

Project Sponsored by
Disability Research Programme of
The Commission for Persons with Disabilities,
Govt. of Mizoram.
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August, 2021

EXECUTIVE SUMMARY





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Prologue

Necessary efforts are made by the Government of Mizoram to implement RPwD Act 2016 in the State. The absence of proper disability studies makes it difficult to know who they are, to ascertain what are the empowerment efforts upto and may aggravate the problems of PwDs. Disability study serves as a sacred mission towards building a more inclusive society. A detailed context-specific study was made relating to the problems faced by PwDs, their needs and expectations in the Aizawl district of Mizoram state sponsored by Department of Social welfare, Government of Mizoram. This document contains nine chapters. Chapter I dealt with Introduction. Chapter II covered the Review of Theories and Models and Chapter III attempted Review of Thematic Literature. Chapter IV detailed out the Research Context and Framework of the study with all procedural details. Chapter V delved into the Socio-Economic Profile of the sample PwD respondents including that of the key informants who worked towards the implementation of RPwD Act 2016. Chapter VI dealt with Rehabilitation Issues faced by the sample respondents and Chapter VII contextualized the concept of Inclusive Development. Chapter VIII went deep into the Role of GOs and NGOs regarding their Accomplishments and to work out future Possibilities. The last chapter summed up the findings towards a conclusion and terminated with a table of recommendations.

Chapter I has been discussed under nine sections. After a brief introduction, the subsequent three sections were devoted to clarifying three concepts like persons with disabilities, rehabilitation and inclusive development. The fourth and fifth sections described the International Scenario and Indian Scenario. North East Scenario was dealt with under the seventh section. Mizoram Scenario relating to persons with disabilities was discussed and the final section spelt out the need for the study.

Chapter II and III are related to the review of the literature. While searching the literature, a huge body of studies and literature was gathered. It was not possible to put them under one chapter. Therefore, the body of literature was reviewed and documented under two chapters: one devoted to Theories and Models and the second one covered the review of thematic (substantive) literature. The idea in Chapter II has been to synthesize the models and theories delineating and critiquing each of the theoretical models emphasizing the dialogue among them to locate their potential contribution to the mainstream disability research. Chapter III is related to the review of substantive literature covering the details of theme, facts and figures, issues, subject area and the analysis of empirical materials.

Chapter IV started off with the following objectives.

- 1. To present the profile of the types of disability and epidemiology of their plight in Mizoram
- 2. To delve into the financial impact of disablement on the family/household and the socioeconomic burden on parents
- 3. To evaluate governance arrangements in taking proactive measures towards mitigation and affirmative action towards rehabilitation and resettlement of disabled in Aizawl District
- 4. To study the role of stakeholders and rehabilitation institutions in tackling the problem of disability in Mizoram.
- 5. To work out the implications of the Mizoram study for preparing an overarching actionable policy framework for the States of North East India.

The present study represents an exploratory- cum -descriptive research design. Aizawl district, which has been earmarked for this study, comprised the universe for the purpose. Stratified random sampling justified through probability proportion to size (PPS) with 10% of the available distribution was used. Total sample chosen was 166 covering 10 localities while the actual number of sample available for Research Project sponsored by Govt. of Mizoram 2019-2021

response were 114 including 3 samples who were not in the original list and they could be available to us only through snowballing. The number of women samples (58) outnumbered the number of men (56). There were 22 KII respondents selected purposively comprising 7 male and 15 females.

The database of the study is drawn from a wide variety of secondary sources while primary data are collected through observation, interview, case study and key informant Interview The analytical framework used in this study has been a combination of qualitative and quantitative techniques. For the quantitative analysis of the data were codified to make it SPSS software friendly. For qualitative data analysis, in addition to the case study, observation and narratives, the method of 'lived experiences', rooted in phenomenological and ethnographic traditions, has been used.

Socio-economic Profile

Chapter V is oriented towards finding out the socioeconomic profile of sample persons with disabilities in Aizawl District of Mizoram. The variables analysed in this chapter to understand the socioeconomic status of the respondents include Gender and Age, Marital Status, Religion, Educational status, Occupation status, Employment status, Place of domicile, Family and Household, Family income, land possessed, Type of Disability and Causes of Disability. All except one practise Christianity as their religion.

- 114 respondents, 58 females are representing 51% and 56 males representing 49%.
- Gender has been taken as an independent variable for the gender differences.
- More of the aged group is found among the male respondents.
- Younger generation disability is found to be more among women.
- Old age disability is more among men than women.
- More than double of the male respondents than the female members are found married. Female respondents (47 out of 58) either found unmarried or if married get separated easily returning to the parental family. Post-marriage separation low among men than their female counterparts
- No widowers among the male respondents, two widows are found.
- Problems in terms of attending higher education as the number is very low for both genders.
- In terms of occupation, the rate of unemployment among women very high as compared to men.
- There were no gender differences in the conditions of persons with disabilities belonging to rural areas against the urban dwellers.
- Nuclear household, More male headed few female headed, Average family size is 4.65.
- The income and the living conditions of the men are a little better as compared to the women. Only a few members belong to the families with income at the lowest range per month.
- A greater number of women PwDs are dependent on family income. There is an inverse variation relationship between the family size and no of earning members in the family i.e more is the family size lesser are the number of earning members per family.
- 73 out of 114 with an average family size of 4.64 had a single earning member.
- Financial pressure is very heavy on 2 families in an 8 membered family and two families in a 9 membered family, managed by a single earning member.
- a greater number of the respondents across gender are landless. But among the landowners, women have found their representation in all categories of land ownership as against men.
- Types of disability
- the highest number of disabilities among the male respondents are blindness and low vision, hearing and any other muscular dystrophy, Parkinson's disease and dwarfism as the

respondents were equally distributed (12) in each of the above-mentioned disabilities. None of the male respondents have a disability in speech and SLD.

 None subscribed to the religious model of disability i.e disability due to past deeds or sin committed

Rehabilitation Issues

Rehabilitation issues of persons with disabilities in the Aizawl district of Mizoram were dealt under chapter VI. Rehabilitation creates an enabling environment to mitigate the deprivations in terms of capabilities or functioning that results from the interaction of an individual's personal characteristics. The discussion of the chapter has been arranged under the following heads: 1. dependence limitation imposed by disability, 2. supportive factors made PwD reduce dependency limitations, 3. confidence of mobility, 4. issues of assistive device, 5. vocational/technical training, 6. rehabilitation problems, 7. adjustment with disability and 8. rehabilitation needs of persons with disability. the penultimate section elaborated four case studies terminating with this overview.

- The women are more dependent on their family members than the males
- No adverse effects disabilities have on their families or the whole household, nor any disabilityrelated financial pressures on their household, nor any arguments and mud throwing among the family member
- The importance of family as the immediate means of support is very clear from their responses as their support, empathy and sympathy appear to have gone a long way in boosting the morale and the quantum of independence of disabled people.
- The male respondents are a little bit more independent on mobility and in using public transport (very high to medium) as compared to the women counterparts. Respondents' extent of independence on their daily living skills was also not very discouraging.
- There were issues about the use of any assistive device, source of obtaining, cost of assistive devices, knowledge of assistive device of communication, across gender.
- Majority of users among vey few attributed assistive devices as 'Not user friendly'.
- 81.6% across gender have voiced their opinion in favour of the higher-order need for skill, vocational and professional training.
- Instances of lack of resource Centers or existing but non-functional or or PwDs are unaware about it. e.g Center for Disability Studies set up by GOI at MZU Campus and lying closed for last three years.
- The respondents emphasized that the rehabilitation towards inclusive development requires several needs to be fulfilled such as the need for guidance and counseling, orientation and mobility training, educational facilities, employment, barrier-free environment, need for association, empathetic attitude, resource Center and educating the public about the challenges and opportunities.

Towards Inclusive Development

Chapter VII covers the thematic areas of inclusive development such as accessibility, educational facilities, employment opportunity and professional training, level of awareness about the legislations and role of legislation in ensuring equality and non-discrimination.

- The respondents could not feel if their needs for inclusive development have ever been met in the context of the extent of having accessibility, the extent of availability of educational and training facilities, employment opportunity and extent of equal treatment including empathetic attitude.
- Majority of the respondents across gender remained silent and did not prefer to respond on the
 extent of inclusive development as they claimed not to be aware of facilities available nor have,
 they ever availed any.

- Most respondents are unaware of the existence of RPWD A 2016 including the State Rules of Mizoram (available in regional vernacular).
- Women and girls with disabilities commonly experience double discrimination that extends to all areas of life, including legislation and policies.
- There are five meaningful case studies. While one felt prouder of her abilities than her disability by working in her family restaurant, others claimed that the hearing-impaired and locomotor disability community are more backward than the visually impaired community. Two of them lament the lack of educational facilities and the problem of affordability. One girl narrated her story of coming from rural Serchhip to urban Aizawl for education but no avail.

Our respondents have quoted saying

- * "Would it ever be possible to think about accessibility of the persons with disability in the same way as the able persons. No, never. The problem can only be mitigated through the best effort of agencies but cannot be eradicated. One has to live with it as and when it comes on one's way. What cannot be cured must be endured. Therefore, I laugh at people who propose to solve the problems of accessibility of persons with disability."
- * "One day I went to the office of the Department of Civil Supplies to sort out issues as a consumer. I could not climb the steps nor the stairs. None cared. I had to return helpless. I talked to the local counsellor who could sort out my problem".
- * "The reason for Ephatha School not opening class 9 onwards is that there are not enough trained teachers in their schools and they also faced certain financial problems. Hence, they could not further introduce class 9 onwards."
- * "when the problem of unemployment is perennial worldwide, it would be just too much to think about solving the problem of employment needs of persons with disability. I attribute it to good fortune of those who have secured their employment somehow through provision of reservation or otherwise".
- Lalnunpuii (Blindness) said "I once had an embarrassing incident with my eye doctor, I cried out from his office". She came to Aizawl from her village for her eye check-up."
- * "I feel like the government hasn't done enough to provide sustainable livelihood for the disabled people."
- * "The blind community has the strongest association."

Role of GOs and NGOs: Accomplishments and Possibilities

Under RPWD Act 2016 every Government (GO) is mandated to provide institutional services and support specifically to enable persons with disabilities to participate in society and lead a dignified life. There is also a strong commitment on the part of the State Government to ensure that the rights of PwDs are protected and well-enforced in the State of Mizoram. The Government of Mizoram state has encouraged non-government organisations (NGO) involvement over the years as facilitators, collaborators and as partners in the disability sector, and more recently to become more active in the area of rehabilitation and inclusive development. In fact, the responses regarding rehabilitation measures, the accomplishment of inclusion and the level of awareness regarding available legislations especially in the capital city of Aizawl have not been quite encouraging amidst all diligence on the part of GOs, NGOs and the beneficiaries themselves across gender.

- The input from the key informants in GOs and NGOs are duly triangulated by examining lived experiences of persons with disabilities.
- Available legislations especially in the capital city of Aizawl have not been quite encouraging amidst all diligence on the part of GOs, NGOs and the beneficiaries themselves across gender.
- Problems are often invisible, severe. Not receiving enough care and support from the public and support agencies. A low level of awareness, inclusivity and participation in various activities

- Being discarded from schools and not being able to access various institutions and public buildings.
- Stigmatization, discrimination, lack of educational facilities, employment opportunities and accessibility to resources are the additional problems faced by persons with disabilities. Improper handling of the disabled in the family especially mentally retarded. Many institutions, Schools not having ramps in them.
- Unavailability of Data and Identification issues
- The cumbersome procedure of documentation and certification

The welfare and progress of disabled people have been slow indeed but that does not mean that their growth and progress are impossible. The key informants were happy to share the future plans of their respective agencies and organisations.

The Commissioner, PwD Government of Mizoram narrated the future plans as.

- 1. Preparation of disability Census, Data Collection and updation and issue of UDID cards
- 2. To make District Level Committee on Disability to be made functional
- 3. Utilization of special fund for disability
- 4. Coordinating with the leaders of City Bus Owners Association to provide a special seat for disabled people inside the city buses.

NGOs, school authorities, community leaders and church elders have given their future plans as:

- 1. Raising awareness and advocacy in collaboration with the Office of Commissioner of PwD
- 2. Skill training for teachers and making disabled self-reliant
- 3. Extending High school to higher secondary school with facilities of vocational training
- 4. Identifying the PwDs and involving the Local and Village Level Task Force to help those poverty-stricken.
- 5. To coordinate with GOs and help the process of issue of UDID cards
- 6. Raising school enrolment and attendance and reducing dropouts
- 7. To make provisions for assistive devices and barrier-free environment
- 8. To conduct more sermon sessions and interactive sessions with the mentally disabled people
- 9. To increase the number of resource centers.
- 10. To help remove discrimination and stigmatization.

Implications of the study

A net balance of aggregate consequences revealed that their expectations have been far more than the support received towards inclusivity. The larger implications of this study have been modelled out graphically for a holistic understanding of the problems of persons with disabilities and for providing actionable recommendations towards the mitigation if not the solution. This model has captured the issue under three layers: input framework, diagnosis and prognosis. These three layers represent a linear upward flow of outcome-oriented processes so that input framework facilitates diagnosis and diagnosis encourages prognosis and the ultimate goal of prognosis is to accomplish inclusive development. Diagnosis and prognosis are the terms used in social pathology. Input framework for this study comprised of Theory and Models, Review of Literature, and Data and Method.

Our analysis subscribes to three out of eight theories reviewed such as Social Model, Human Rights Model and disability own perspectives in the context of inclusive development of persons with disability. The theoretical models go on to exhibit that there has been a definite shift from 'needs-based intervention' to 'rights-based approaches' in a given social context where the voice of the disabled is nonetheless important. Similarly, Data evidence gathered under due methodological procedures provided necessary inputs for the diagnosis of key issues. While analysing the data inputs, twenty-five conceptual parameters were identified as the key issues.

- 1. Accessibility issues
- 2. Community Support problems
- 3. Dependence limitation problem
- 4. Employment opportunity being unavailable
- 5. Equality and Non-discrimination issues
- 6. Exclusion and stigmatization problems
- 7. Family Coping difficulties
- 8. Funding and Sponsorship issues
- 9. Guidance and Counselling issues
- 10. Inadequacies in Barrier-free Environment
- 11. Inadequate Educational facilities
- 12. Infrastructure and resources being limited

- 13. Inter-agency coordination problems
- 14. Issues of an assistive device
- 15. Lack of Awareness
- 16. Lack of Confidence of Mobility
- 17. Low Socio-economic profile and poverty
- 18. Monitoring and evaluation issues
- 19. Problem of Adjustment with disability
- 20. Psychological stress
- 21. Public sentiment incompatibility
- 22. Rehabilitation problems
- 23. Role of legislation and Implementation difficulties
- 24. Skill training needs
- 25. Vocational/technical training issues

These key issues need to be addressed through due prognosis. A prognosis is made by looking at the nature and nuances of the diagnosed problems, the lived experiences of the person with a disability, the available amelioration efforts, and the related issues. A complete prognosis includes the expected duration, function, and description of the course of the problem, such as possible implementation measures and progressive mitigation of the issue at hand. Prognosis stands at the midpoint of development interventions from where one can look back to what has been done and look forward to what can be done ahead. It is neither on man's job nor one agency's work. It requires multiple support systems across agencies and institutions through interagency coordination so that the problems of the persons with disabilities can be addressed and their sufferings can be mitigated. The support system from the agencies and institutions such as Family, Community, School, Church, Associations, NGOs, Resource Centers, Public and GOs, need to be geared up and the present condition of inter-agency coordination must be improved.

Suggestions and Recommendations

There are a lot of challenges in the implementation of the RPWD Act 2016 and getting the problems of the disabled community mitigated. It is not impossible in its full sense. What is being emphasized is the need to gear up the support system, create awareness and promote greater inter-agency coordination towards such accomplishment, more so in rural areas. The very goal of an inclusive development program for PwDs can be met by abridging the gap between physical disability and social discrimination through mutual acceptance, realization, empathy and adjustment between individuals and society. The office of the Commissioner for Disability, Mizoram needs to continue to remain vigilant and become a "Watchdog" on the implementation process by every department and from time to time to make a review of the situation and give guidance to the concerned departments, then the situation could improve much faster. The office of the Disability Commissioner is not one of the departments of the State Government as mandated under the said act. It must function as an autonomous agency with all its judicial power embedded. Suggestions and recommendations in terms of each indicator, are presented below.

1. All facilities under RPWDA 2016 should be made accessible to PwDs by making them sufficiently aware. Ramps should be established in every Churches, public institutions and offices.

- 2. The disabled people should be provided with educational and medical facilities and should also be given employment opportunities. Care must be taken against the misuse of job quota for PwDs by non-disabled persons.
- 3. Care must be taken such that disabled students have the right to be admitted in any school that they wish to attend. Hostel facility should be available with adequately trained care givers for students and working persons with disabilities.
- 4. Local availability of assistive devices for the disabled people through public private partnership should also be encouraged by the government. More funds should be provided by the government to the disabled people to help them and ease them in acquiring assistive devices.
- 5. Surveys should be carried out among the disabled people asking them about their needs of devices and in turn, take all necessary actions and measures to meet their needs.
- 6. Adequate awareness should be created through village and local councils, social media, newspapers, radios and televisions for disabled, families, community and caregivers and to make the general public aware of the hardships and problems faced by the disabled people.
- 7. Awareness should be carried out among school level and college level students which could impart an understanding on the lives of PwDs at an early age.
- 8. Awareness should be carried out on RPWD ACT 2016 to different government departments so that the Act and its various provisions could be effectively implemented. Non-compliance by line departments be monitored and actions be initiated.
- 9. Steps should be taken to include more ramps in public institutions. Participation of the disabled people should be increased and non-discriminations be ensured.
- 10. Awareness towards the importance of uplifting PwDs should be carried out more often and Community Based Rehabilitation Centres should be established which is beneficial to meet the needs of the disabled people. Adequate strategic Community Based Rehabilitation be made available in inaccessible and rural areas
- 11. Increased usage on assistive devices should be encouraged among the disabled people. Besides mobility trainings should also be given to the PwDs and skill training for an independent livelihood should also be encouraged by the families, caregivers and line departments of Government.
- 12. There is a high need to provide opportunities for education of deaf and hearing impaired beyond Class VII in special Schools. Provision of more Special Educators at the Block level should be made by the authorities which can be beneficial for the education of PwDs. There is a need to have more specially trained teachers and persons who are expert in dealing with PwDs to aid in guidance and counselling.
- 13. All schools must be taken over by the Government so that infrastructure could be developed and Grant-in aid could be provided. Teachers should be trained so as to gain knowledge to look after the disabled students in a more effective way. All the salaries of the teachers should be paid as per approved by the government.
- 14. Intensive surveys and job analysis should be performed so that occupational classification can be made and classification of jobs can be made to suit the efficacy of various categories of PwDs. The government should organise skill training and private sectors should ease their employability and livelihood.
- 15. Job-specific placement training should be provided soon after joining.
- 16. Provision of Old Age Pension and Unemployed Graduate youth pension should be introduced and properly implemented by the government.
- 17. More awareness towards giving equal chances to disabled people in schools, work places and jobs with non-disabled counterparts should be carried out and its implementation should be ensured as well.
- 18. There should be more representation of disabled people in the media, Churches and community and there should also be increase level of awareness among the people.
- 19. Parents should be accepting the disabilities of their child/family members and they should not neglect them in any way.

- 20. There is a need to access fund allocated through National Handicapped Finance and Development Corporation. Special funds for the disabled people should be released and utilized in a proper manner. Government policies should be monitored and evaluated so as to enable increase in funding and scholarships for the disabled people. Funds should be properly reserved and provided by the government and the correct usage of the funds should be ensured as well.
- 21. Financial assistance should be provided to the cases of marriage between differently able and able persons.
- 22. Village/ locality level household Census should be prepared so that UDID card could be issued for the disabled people.
- 23. State level Data Base on Disabilities should be created and existing be updated.
- 24. Periodic meeting with GOs. NGOs and line departments and outcome should be circulated to members and further monitoring towards compliance of actionable suggestions.
- 25. Support of NGOs and churches in advocacy initiatives should be supported at all cost.
- 26. To have a quick survey on problems faced by PwDs in usage of assistive devices and to make their availability free of cost.
- 27. Wheelchair lane should be established on the side of the road for disabled by-passers. There should be special parking slots assigned with mark for PwDs in garage and in every parking place.
- 28. Sitting arrangements should be reserved for the disabled people in public transport, especially in that of buses. Encouraging the practise of more mobility orientation and training of the disabled people by the authorities.
- 29. The government should keep a strict vigil over the implementation of RPWD Act 2016. Monitoring and evaluation of Governmental Plan, Policies, program and legislation in order to ensure its avowed outcome. Practise of introducing certain intensive surveys and occupational classification among the PwDs.
- 30. Free helpline numbers should be available to counsel and comfort the PwDs and their families in times of crisis and stress.
- 31. Advocacy and Awareness should be intensified through NGOs under Government assistance and funding.
- 32. Short films should be made and street plays should be organized which depict the difficulties and struggles of the PwDs to awaken people's empathy towards the disabled people. There is a much need towards the building of empathy-led -sympathy actions among the general public.
- 33. To establish more rehabilitation centres in the state to cater to the needs of the PwDs. Non-functional resource centres should be made functional. There are many non-functional resource centres in the state and it would be highly beneficial if the government could make them to be functional.
- 34. Government should put more effort to have a reliable and proper socio-economic profiling of the PwDs for need based equal support services for all types of disabilities.
- 35. To request selected people from outside the state to impart training to the PwDs and the care givers and also to disseminate the same acquired knowledge through subsequent training in the process.

Persons with disabilities can prove beyond any doubt that given equality of opportunity they have the inherent potential of becoming active agents of change rather than remaining passive recipients of benefits. Though working in the disabled sector has been a long hard haul, it is heartening to see people in academia, in government, and in civil society, finally use their brain and pen and addressing issues that have been long pending such as - a barrier-free environment, inclusive education, job reservations, equal opportunities to enable full participation in all walks of life, and umpteen others. Hearts and mindsets need to truly shift gears today to help understand catchphrases such as 'nothing about us without us,' 'disability is not a welfare issue, it is a development issue,' 'value us as part of the human resource,' 'not pity, but respect' and so on. Inclusiveness should be viewed from the victim's point of

view, and this view should also extend to their caregivers, their families. This document concluded with the hope that this study has met its desired goal and its outcome will play a vital and significant role for the differently-abled population of North East region in general and Mizoram in particular, to claim their rightful place both in letter and spirit.

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@ REHABILITATION AND INCLUSIVE DEVELOMENT OF PwDs Data and Method Theory and Models Literature Analysis The Moral and Religious model Input Framework Identification Data collection Medical Model Observation Interview Social Model •KII •FGD Case study Charity Model Social Mapping Analysis and Interpretation nan Rights Model Description Exploration Ferninist and Gender Theories Explanation Lived Experiences Triangulation ability Own Perspectives Narratives Mixed Methods ical Disability Theory SPSS for quantitative data Diagnosis Prognosis Community Support System Inter-Agency Coordination School Associations NGOs Resource Centres Public

-Thank You-