

**STATE AND THE ISSUE OF DISABILITY: A
STUDY OF THE FUNCTIONING OF THE STATE
INSTITUTIONS RELATED TO DISABILITY IN
ASSAM**

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This is to certify that this thesis entitled "State and the Issue of Disability : A Study of the Functioning of the State Institutions related to Disability in Assam" by Smti. Trishna Rani Borah, Assistant Professor in Political Science, B. Borooh College, Guwahati is submitted for the award of the Degree of Philosophy (Ph.D) under Surya Kumar Bhuyan School of Social Sciences at Krishna Kanta Handiqui State Open University. This thesis has been evaluated using the urkund D110189675 which found it in order as per UGC's plagiarism policy and instructions issued from time to time. This research work is carried out under my guidance and supervision and fulfills all the requirements under the Ph.D regulations of the University.

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Trishna Rani Borah

LIST OF ABBREVIATIONS USED

ACCD	American Coalition of Citizens with Disabilities
ADA	American with Disabilities Act
ADIP	Assistance to Disabled Persons for Purchase/fitting of Aids and Appliances
AIDS	Acquired Immunodeficiency Syndrome
CBO	Community Based Organization
CBR	Community Based Rehabilitation
CBVT	Community Based Vocational Training
CDS	Centre for Disability Sports
CEDAW	Convention on All forms of Discrimination Against Women
CIVE	Centre for Inclusive and Vocational Education
CRC	Composite Regional Centre
CRC	Convention on the Rights of the Child
DAV	Disabled American Veterans
DDA	Disability Discrimination Act
DDRC	District Disability Rehabilitation Centre
DDRS	Deendayal Disabled Rehabilitation Scheme
DEI	Disability Employment Initiative
DGET	Directorate General of Employment and Training
DPEP	District Primary Education Programme
DRC	District Rehabilitation Centre
DRDA	District Rural Development Agency
DRG	Disability Rights Groups
EIU	Early Intervention Unit

EVM	Electronic Voting Machine
HIV	Human Immunodeficiency Virus
IBR	Institution Based Rehabilitation
ICCPR	International Covenant on Civil and Political rights
ICERD	International Convention on the Elimination of All forms of Racial Discrimination
ICPMW	International Convention on the Protection of the Rights of All Migrant Workers
ICESCR	International Covenant on Economic Social and Cultural Rights
IECD	Integrated Education for Disabled Children
IIE	Indian Institute of Entrepreneurship
NCVT	National Council for Vocational Training
NEDFI	North Eastern Development Finance Corporation Ltd
NFB	National Federation of the Blind
NGO	Nongovernmental Organization
NHFDC	National Handicapped Finance and Development Finance Corporation
NIOH	National Institute for Orthopedically Handicapped
NIRD	National Institute of Rural Development
NPE	National Policy on Education
NPRPD	National Programme for Rehabilitation of Persons with Disabilities
NTA	National Trust Act
PCEH	Presidents Committee on the Employment of the Handicapped
PIED	Project for Integrated Education of the Disabled
PNRD	Department of Panchayat and Rural Development
POA	Programme of Action

PRA	Primary Rehabilitation Assistant
PRU	Primary Level Rehabilitation Unit
PWD	Persons with Disabilities
RADAR	Royal Association for Disabled Community
RCI	Rehabilitation Council of India
RPWD	Rights of the Persons with Disabilities
RTE	Right to Education
SIPDA	Scheme for Implementation of the Persons with Disabilities
SIRD	State Institute of Rural Development
SSA	Sarva Shiksha Abhiyan
UDHR	Universal Declaration of Human Rights
UNCRPD	United Nation Convention on Rights of the Persons with Disability
UNDP	United Nations Development Programme
UNICEF	United Nations Children Emergency Fund
UPIAS	Union of the Physically Impaired Against Segregation
VOADL	Voluntary Organization for Anti-Discrimination Legislation
VRC	Vocational Rehabilitation Centre
VRW	Village Rehabilitation Worker
WHO	World Health Organization

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CHAPTER I

STATE AND THE ISSUE OF DISABILITY

1.1: Introduction: Conceptualizing Disability:

In common parlance, disabled people refer to a group of people who are not being able to do something due to their abnormal body or intellectual incapability. They cannot engage in common activities of the society because of their physical or mental inability. The term disability, impairment, handicapped, physically challenged and so on are used interchangeably to denote the inability of this section of the society. However, certain kinds of limitation are common to all human being at different stages of life. For instance, in the childhood some activities cannot be performed because of bodily immaturity. Similarly, in the old age due to the natural decline of physical capability certain restrictions automatically come to human body. In that sense, all human beings are temporally able bodied person. Therefore, like health and sickness, ability and disability are linked with various facets of life, viz., medical, economic, vocational, legal and bureaucratic and so on. It is worthwhile to mention here that from time to time, from place to place and from person to person the terminology of disability has undergone changes. For centuries, the term 'crippled' was used to denote the individuals with physical abnormalities or defects of some kind or other which implies some sort of social stigma and ostracization. Terms like 'disabled', 'physically handicapped', 'persons with disabilities' and 'physically challenged' etc are recent innovation as a result of the growing awareness for the rights and equitable status of the disabled community. Apart from these, disability has various psychological and sociological dimensions too. Psychological dimension includes the impact of disability on individual person, whereas sociological aspect deals with role, status, normative framework and sub-cultural features in a given society (Karna, 2001, p.26). However, the term disability includes only those persons who have permanent deficiencies/impairments for their life. The deficiencies may be congenital or acquired. Besides, physical and mental disability are two dimensions of disability. Orthopedic

disability, blindness, low vision, paralysis by birth or even afterwards, inability to hear or speak properly and other related problems are considered as physical forms of disability. On the other hand, mental disability is about those who suffer from any psychological syndrome that causes a feeling of distress or disables an important area of their mental faculty (The New Encyclopedia Britannica, 1987)). Besides, the term disability can broadly be understood in five ways (Townsend, 1973, pp.110-115). Firstly, a person's anatomical, physiological or psychological abnormality or loss can consider as disability. Hence, loss of a limb or part of the nervous system through surgery or in accident or become blind or deaf or paralyzed etc are some conditions of disability. Secondly, the chronic clinical conditions such as bronchitis, arthritis, tuberculosis, epilepsy, schizophrenia and so on usually interrupt normal physiological and psychological process and lead to a state of disability. Thirdly, functional limitation of a person or incapacity of self care and management i.e., not being able or finding it difficult to move about, negotiate stairs, wash and dress is regarded as disability. Fourthly, disability can be defined as a pattern of behaviour which is generally termed a socially deviant behaviour. Because of pathological condition or impairment, the activity of a disabled person is not only restricted but also dissimilar which is very much dependent on how it is perceived by the individual and other as on physiological determination. It needs to be mentioned here that society anticipates the blind or the deaf or the physically challenged to behave in certain stereotypical manner (ibid, p111). Fifthly, disability refers to a socially defined position or status, thereby attracting a mixture of deference, condescension, consideration and indifference. Again, depending on the nature of societies, the causes of disability also vary. For instance, in developed countries disability problem is found among the industrial workers or old persons and in developing countries malnutrition, poverty, unhygienic situation and so on are the main causes disability. However, war, disease, malnutrition, industrialization etc are regarded as common causes of disability irrespective of any kind of society and the disabled persons are always been considered as subject of welfare, charity and protection and sometimes as the subject of exclusion.

1.1.1 Malnutrition and Disability:

While conceptualizing disability a brief reference could also be made to that of malnutrition. Malnutrition in its different forms causes disability and sometimes leads to certain conditions in other ailments that increase susceptibility to disabling conditions which include (Disability Manual,2005, p.22):

- Vitamin A Deficiency-Blindness
- Vitamin B complex deficiency- beri-beri (inflammation or degeneration of the nerves, digestive system and heart), pellagra (central nervous system and gastro-intestinal disorders, skin inflammation) and anemia
- Vitamin D deficiency- rickets (soft and deformed bones)
- Iodine deficiency: slow growth, learning difficulties, intellectual disabilities and goitre
- Iron deficiency: anemia, which impedes learning and activity, and is a significant cause of maternal mortality
- Calcium deficiency- osteoporosis (fragile bones)

1.1.2 Wars and Disability:

Human civilization right from its beginning has witnessed different types of war at various points of time which causes permanent disablement to human kind. The use of lethal, chemical and nuclear weapons, brings disability not only to the combatants in the battlefield but also to civilians who are forced to bear the hazards of these weapons. It is believed that twenty five percent of the world's population is suffering from the consequences of war and civil conflict (Mann, 1999). Based on figures from a study carried out in 206 communities, including Afganistan and Cambodia, landmine triggered disability rate among survivors is about 0.9% (Mann,1999). Besides, physical and psychiatric disabilities in war ragged countries emerge not only because of war

injuries but are caused more by diminishing resources and growing demand on already scarce resources available to communities.

1.1.3 Different Models of Disability:

Broadly, Disability can be viewed from two aspects - individual and social model of disability. The individual model or medical model focuses on physical, sensory and intellectual impairments as factors for the difficulties faced by persons with disability. Therefore, individual/ medical model entrusts the role of medical and paramedical professionals to cure or ameliorate the condition of disease to enable the people with disability to live a normal life. Based on the personal tragedy paradigm, the medical model treats disability as impairments where power to control, define and treat those impairments lies in the hands of medical and paramedical professionals. On the other hand, the social model is critical of the social structure, which is not accommodative to fulfill the needs of the persons with disabilities (Ferri and Noel 2015). Therefore, disability is understood as oppression by social structures and practices and the oppression works on the individuals denying or diminishing personhood, citizenship and civic participation (Kayess and French, 2008). Within the two broad models of disability i.e., individual model and social model, the four identifiable formulations viz., the charity model, the bio-centric model, the functional model and the human rights model are also important to understand the issue of disability from a deeper perspective (NHRC,2005).

- **The charity model** considers the persons with disabilities as helpless victims needing care and protection and is based on the goodwill of benevolent humanitarians for ‘custodial care’ of the disabled. Rather than justice and equality, charity and benevolence are the main focus point of social responsibility in this model. The charity model assumes that claims to rights is valid on certain grounds and invalid in certain others and creates the individuals a beneficiary rather than stakeholder. Establishment of special Schools, sheltered workshops and protection homes for persons with disabilities by various religious and other philanthropic agencies are some instances of charitable

model of disability. Instead of bringing education, vocational training and right to safe and secure shelter for disabled persons under the direct purview of their development agenda, many governments provide financial grant to them.

- According to **the bio-centric model** of disability, disease, physical or mental disorders etc are the main causes of disability and can be reduced through medical intervention. The medical intervention primarily aims to prevent disability and bring the individual's embodied experience in line with established standards of normalcy. In comparison to the conventional norms of a normal human being, the bio-centric model locates persons with disabilities as 'abnormal' hence undeserving and dangerous (Cohen 1985). Although in contemporary time biology is no longer the only determining factor in disability legislations, it has a great role not only in finding out eligibility and entitlement to benefits but also influences access to rights and full social participation.
- **The functional model** of disability tries to explore the disparity between the individual's biological condition and functional capacities on the one hand and environmental and situational factor on the other. It aims at making individual as functional as possible by treating perceived incapacity through services and supports as required. This involves compensation rather than cure for people with disabilities to live their lives that are as 'normal' as possible (Meyer, 1990). Rehabilitation services like physiotherapy and occupational therapy including training in daily living skills, pre-vocational skills, functional assessments, counseling and job training etc can enhance the functional skill of the persons with disabilities.
- **The human rights model** recognizes disability is an important dimension of human culture and avows that all human beings irrespective of their disabilities have certain rights which are inalienable (NHRC,2005). Hence, the human rights model is based on the spirit of the Universal Declaration of Human Rights, 1948, according to which, 'all human beings are born free and equal in rights and dignity.' However, in international human rights law, two complementary principles viz, non-discrimination and reasonable differentiation play an important role in defining the concept of equality. As the disabled persons

require some sorts of specialized services or support in order to be materially equal to others, the principle of differentiation is not considered as discriminatory if it is based on 'reasonable and objective justification'.

1.1.4 Socio-political Perspective of Disability:

Disability can be viewed from socio-political perspective, emerges as a result of interaction between a person's impairment and the physical social environment and a disabled individual apart from his/her physical or mental limitations encounters social oppression in day-to-day life (Karna, 2001). For the understanding of disability from a social science perspective, disability studies encompass four dimensions (Locker, 1983). In the first place, epidemiological study of disability is mainly concerned with the identification and measurement of chronic illness. Since the late 1960s particularly in the context of western societies government initiatives were made for the documentation of numbers and needs of the disabled people (Townsend, 1973). The second category is about rehabilitative measures, which try to explore the social and psychological factors influencing behavioural responses to disease and injury (Fross et al, 1980, pp485-90). The third category comprises of the problems of disabled people and welfare dimension of their solution. Fourthly, disability can be understood from a theoretical perspective by using diverse sociological tools.

1.1.5: Marxist Perspective of Disability:

The Marxist perspective of disability depends on functionalism referring to a person's utility to his community and environment (Barnes, 1997). This perspective emerged with the rise of industrial capitalism. According to Marxist perspective, in an industrial society the disabled people are always being oppressed and stigmatized as they could not sell their labour power because of their physical limitations. Hence, the notion of normalcy is very much related with the capitalist mode of production.

Disability Studies scholar Michael Oliver has provided the Marxist analysis of disablement in the following manner (Oliver, 1999)-

Normalization theory offers disabled people the opportunity to be given valued social roles in an unequal society which values some roles more than others. Materialist social theory offers disabled people the opportunity to transform their own lives and in so doing transform the society in which they live into one in which all roles are valued (p.172).

1.1.6: Feminist Perspective of Disability:

The feminist perspective on the body has also provided a new perspective to disability studies in contemporary time. The feminists argue that the body itself is a site of ideological contestation. The feminist disability scholars and activists enunciated the premise that the experiences of impairment are central to the women life. A disabled imperfect female body signifies the absence of femininity and social unacceptability as female subjectivity is so deeply intertwined with embodiment in a patriarchal society. Since women with disabilities do not look like normal women and their bodies do not function like normal bodies in some respects and they cannot play the role of a normal woman, they are considered as less than women (Addlakha, 2013). According to Michelle Fine, the image of a women as a care giver is a significant component of normative construction of femininity, but a woman with disability is herself in need of care. This also locates the women with disability in a life of a social isolation (Fine & Asch, 1988).

1.1.7: Postmodernist Perspective of Disability:

The postmodernist and poststructuralist researchers of disability studies have provided another perspective of disability that shifts the primary focus from socio-structural determinants to linguistic, discursive and cultural practices. Rather than configuring it as a fixed essential category within a definite genesis of capitalist social formation, the postmodern perspective looks at disability through the category of power, knowledge and social construction. For them, disability itself is a relational concept. It interrogates the medical model that projects normalcy as a taken for granted notion.

They configured normalcy as an ideological hegemonic construct rather than an actual condition of embodiment. Indeed, disability is intensely a common faith of all bodies and not just impaired bodies. The postmodernist perspective further argues that all human bodies are only temporarily able body. The ideal normalcy is an attempt to conceal the association with fear, vulnerability and death that the disabled body evokes in the abled bodied minds (Addlakha, 2013). According to Gofman, the ideal type normal individual is also socially constructed by modern western societies as young, married, white, urban, northern, hetero- sexual, fully employed of good complexion, having standard weight and height. On the other hand, persons expressing differences such as homo-sexual, non-white, unemployed, unmarried and short persons are excluded from the normal ideal type subject position. Similarly, disabled people are also considered to be deviants from the definition of ideal type norms. However, this definition of ideal type constructed by modern western society was challenged by the feminist movements in the twentieth century in Africa and America. In recent times disability rights movements in different parts of the world has also followed the same trajectory of challenge and assertion of difference as a legitimate subject position in a pluralistic society. Thus, postmodernist perspective has provided a new meaning to the social model of disability studies.

1.2 Definitions of Disability:

As mentioned earlier, traditionally disability was considered as an issue of medical intervention and gradually it has broadened its horizon towards the complex social milieu. The evolution of disability studies as a separate subject of academic discipline emerged aftermath of various disability movements particularly in the western land has extended the traditional concept of disability. It is therefore important to discuss the various definitional framework of disability given by various organizations, conventions, declarations and so on for a better understanding of the subject matter.

Dorland's Illustrated Medical Dictionary defines disability as lack of the ability to function normally, physically or mentally, anything that causes disability (Sekhar, 2009, p.6).

Similarly, the Illustrated Stedman's Medical Dictionary describes disability as medico-legal term signifying loss of function and earning power (Sekhar, 2009, p8).

The General Assembly of the United Nations has defined disabled persons as ---- any person unable to ensure by himself or herself wholly or partly, the necessities of a normal individual and or social if as result of a deficiency, either congenital or not, in his or her physical or mental capabilities (Supra Note 3).

It is worthwhile to mention here about the International Classification of Impairments, Disabilities and Handicaps (ICIDH) created by the World Health Organization in 1980s for the better evaluation of the effectiveness of health care processes for chronic diseases, disorders and impairments which recognized disability, impairment and handicap as distinct entities focusing on environmental barriers. Hence, this classification discussed disability beyond medical model which is not adequate to understand the conditions which are not acute and temporary.

According to the UN Convention on the Rights of the Persons with Disability 2006, 'Persons with disabilities include those who have` long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'(CRPD,2008).

Disabled People's International (DPI), a world federation of organizations of disabled persons has defined disability as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers. (Supra Note2)

According to the Americans with Disabilities Act (ADA), A physical impairment is any psychological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organ, respiratory(including speech organ), cardiovascular, reproductive, digestive, genitourinary, hemic and lymphatic, skin and endocrine.

Again UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993 describes 'disability as a socially created problem which emerges due to a dynamic interaction between health conditions and other personal factors (age, sex, personality or level of education) on the one hand, and social, physical and environmental factors on the other hand (NHRC 2005, p. 20).

The Declaration on the Rights of Disabled Persons (1975) defined a disabled person as any person who is unable to ensure by himself or herself, wholly or partly, the necessities of a

normal individual and or social life as a result of a deficiency, either congenital or acquired in his/ her physical or mental capabilities (Addlakha, 2013). The Declaration also stated that “disabled persons” have rights to medical, psychology and functional treatment in order to “enable them to develop their capabilities and skill to the maximum”, with the goal of “social integration”.

International Labour Organization in its International Labour Vocational Rehabilitation and Employment (Disabled Persons) Convention 1983 (No159) and Recommendation 1983 (No 168) defines the term disabled, as “an individual whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognized physical or mental impairment.

The Disability Discrimination Act (DDA) of United Kingdom defines a disabled person as someone who has a physical or mental impairment that has a substantial and long term adverse effect on his or her ability to carry out normal day-to-day activities.

According to the World Health Organization (WHO), Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives.

According to the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, India, disability includes Blindness, Low vision, Leprosy-cure, Hearing impairment, Locomotor disability, Mental retardation and Mental illness.

According to the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, a person with disability means a person who is suffering from any of the conditions relating to autism, cerebral palsy, mental retardation or a combination of any two or more of such conditions and includes a person suffering from severe multiple disability.

More recently the Rights of Persons with Disabilities Act 2016 has defined persons with disability as a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others (The RPWD Act 2016).

1.3 Disability at the International Level:

At the international level under the initiative of United Nation Organization (UNO) various efforts have been made at different point of time for the protection and promotion of human rights. These initiatives can be classified into two categories viz, soft laws include UN declarations and Resolutions and hard laws comprise of UN core treaties. The Universal Declaration of Human Rights (UDHR) passed by UN General Assembly on 10th December 1948 was the first of its kind where basic emphasis was given on human dignity irrespective of any category. Likewise, International Covenant on Civil and Political Rights (ICCPR) 1966 and International Covenant on Economic, Social and Cultural Rights (ICESCR) 1966 have also referred to the rights and dignity of all the human being. However, there was no specific reference of disability as a category and it was remained as a condition which needs rehabilitation, social protection and welfare. The General Assembly, Economic and Social Council and its subsidiary organ, the Social Commission initiated certain programmes for technical cooperation, rehabilitation and vocational dimension. For instance, the social commission during its sixth session in 1950 adopted the reports entitled “Social rehabilitation of the physically handicapped” and “Social rehabilitation of the blind” (United Nations. UN Enable. Chapter III: The early years. Available at <http://www.un.org/esa/socdey/enable/dis50y20.htm>). Apart from these, in 1950 United Nation entities including the International Labour Organization (ILO), the World Health Organization (WHO) and the United Nations Children’s Emergency Fund (UNICEF) established international standards for education, treatment, training and placement of persons with disabilities. In 1969, UN General Assembly adopted a declaration, emphasizing the need to protect the rights and welfare of the persons with disabilities with the intention for the full participation in the society (Declaration on Social Progress and Development, G.A. res. 2542 (XXIV), 24 U.N. GAOR Supp.(No.30) at U.N.Doc.A/7630 (1969), available at (<http://daccess-dds-ny.un.org/doc/RESOLUTION/GEN/NRO25676.pdf?OpenElement>)). Subsequently in 1970s two international instruments viz. Declaration on the Rights of Mentally Retarded Persons 1971 and The Declaration on the Rights of the Disabled Persons 1975 were adopted by the General Assembly which recognized various societal barriers for full

participation of persons with disabilities in society. The declaration on the Rights of Mentally Retarded Persons, 1971 gave emphasis on the role of education for the persons with intellectual disabilities to reach their full potential and to raise awareness about their rights. But, the declaration was retained on the medical/welfare model of disability focusing on social security, welfare and separate services and institutions for persons with disabilities (Declaration on the Rights of the Disabled Persons, G.A.Res 2856(XXVI), at 93, UN, GAOR,Supp.No.29,U.N.Doc.A/8429 (Dec,20,1971), Art.1;prml.5). It is worthwhile to mention here that a transition was found from medical/welfare model of disability to social/human rights model for promoting equal rights and opportunities for persons with disabilities in the Declaration on the Rights of the Disabled Persons,1975. The Declaration stated that disabled persons have right to medical, psychological and functional treatment in order to “enable them to develop their capabilities and skills to the maximum”, with the goal of “social integration” (<https://www.ohchr.org/en/professionalinterest/pages/rightsofdisabledpersons.aspx>).

Besides, Declaration on the Rights of Deaf-Blind Persons 1979, International Year of the Disabled Persons 1981, International Decade of Disabled Persons (1983-1992), World Programme of Action concerning Disabled Persons 1982, The Standard Rules for the Equalization of Opportunities for Persons with Disabilities 1993, Principles for the Protection of Persons with Mental Illness and for the improvement of Mental Health Care 1991, Proclamation of the Economic and Social Commission for Asia and the Pacific on the Full Participation and Equality of the People with Disabilities in the Asian and Pacific Region 1993 are some of the soft laws initiated by UNO for the protection of disability rights. As regards hard laws, United Nation Convention on Rights of the Persons with disability (UNCRPD hereinafter) 2006 was the first international treaty for the protection of the rights and dignity of the disables people. However, International Covenant on Civil and Political Rights (ICCPR) 1966, International Covenant on Economic, Social and Cultural Rights (ICESCR) 1966, Convention Against Torture and Other Cruel, Inhuman, or degrading Treatment or Punishment (CAT) 1984, International Convention on the Elimination of All forms of Racial Discrimination (ICERD) 1969, Convention on the Elimination of All forms of Discrimination Against Women (CEDAW) 1979, Convention on the Rights of the Child (CRC hereinafter) 1989, International Convention on the Protection of the Rights of All

Migrant Workers and Members of their Families (ICPMW) 1990 etc have recognized equal dignity and rights for all the human being. It needs to be mentioned here that these treaties did not deal with issues like reasonable accommodation and inclusion, which would be necessary to make these rights equally available to persons with disability (Kothari, 2012). But the CRC 1989 had an exception to it. In the article 23 of the CRC, state parties were directed to recognize the rights of children with disabilities to enjoy 'full and decent' lives and participate in their communities (CRC, n517, Art23). On the other hand, the UNCRPD 2006 has made paradigm shift in the field of disability as it has focused on capability and inclusion: on lifting the environmental and attitudinal barriers that prevent persons with disabilities from full inclusion and equal participation in all aspects of community life (Kothari, 2012, p.179). It is the first international treaty that has interpreted the dichotomy includes both civil and political rights provided by anti-discrimination legislation (negative rights) with the full spectrum of social, cultural and economic measures (positive rights) conferred through certain equality measures. It needs to be mentioned here that UNCRPD has tried to combine the positive obligations with civil and political rights in the form of reasonable accommodation. For example, Article 5 (para3) of UNCRPD mentions that '*In order to promote equality and eliminate discrimination, State parties shall take appropriate steps to ensure that reasonable is provided.*' Hence, it can be said that UNCRPD has provided a detailed disability specific interpretation of prevailing human rights at the international level, as a result of which a shift has been witnessed from existing non-interference based rights to positive state obligations.

1.4: Voice of the Disabled Persons Around the World: A Social Movement Perspective:

It is worth noting that in contemporary time the issue of disability has witnessed a transformation from welfare or charity model to a right based model. Different disability movements emerged in different countries paved the way for the enactment of a number of disability legislations to protect the rights of the persons with disability. Hence, it is essential to explore the trajectory of disability movements to understand the

larger spectrum of disability. Although between the two world wars (Lenihan, 1976-77) some formal associations for disabled people like Disabled American Veterans (DAV), and the National Federation of the Blind (NFB) were formed in the United States, the disability movement for social inclusion of disabled persons was started only in early 1960s in United States following in the wake of the race, gender and other civil rights movements. The associations formed between two world wars gave emphasis only to fulfill some particular interests (Addlakha, et al, 2009: 354). However, the movements started in 1960s were basically for the identity formation of the disabled people, what they call social ‘oppression’. It is noteworthy to mention here that the social model of disability has contributed towards the raise of the issue like identity formation within the disability. Hence, it can be said that the disability movements started during 1960s have redefined the issue of disability as a political category and also tried to provide a new impetus in which persons with disabilities could represent themselves, live their lives, and campaign for their rights (Malhotra, 2008). According to Hessa Al-Thani, “The disability movement is becoming a global force for change, with increased collaboration among disability groups, between the disability community and governments, and between the disability community and human rights community” (Thani, 2004). However, the growing potential for political activism is not enough to ensure the growth and proliferation of disability movements as well as inclusion of the demands by the persons with disability at policy level. By the early 1970s many organizations like President’s Committee on the Employment of the Handicapped (PCEH), American Independent Living Movement (ILM) and so on were formed in America in order to provide education, rehabilitation and most importantly employment for the disabled people. In 1974 PCEH and other disability organizations of America altogether formed American Coalition of Citizens with Disabilities (ACCD). At that point of time ACCD was not only considered as the cross-disability organization, many organizations like National Centre for law and the handicapped in South Bend, Indiana, the Disability Rights Centre in Washington, D.C, the National Association of the Deaf, the Paralyzed Veterans of America etc also became the part of ACCD. ACCD helped to organize the nationwide civil disobedience campaign which put pressure on the US Department of Health, Education and Welfare to promulgate regulations implementing Section 504 of the American 1973 Rehabilitation Act; legislation which attempted to

prohibit discrimination against disabled people to an extent. The American with Disabilities Act 1990 (America's most comprehensive Disability Legislation) was also influenced by ACCD. In Britain too, organizations like Union of the Physically Impaired Against Segregation (UPIAS), Liberation Network, Sisters Against Disability and so on were formed in 1970s for securing equal rights for disabled people and the removal of negative discrimination in all its forms (Barnes, Oliver and Barton, 2002). Among these organizations, UPIAS was instrumental in fighting widespread and systematic exclusion of the disabled people from the economic and social life. Lots of demonstrations and civil disobedience campaigns initiated by the disabled people and their supporters against a range of issues including: inaccessible environment, pedestrianisation, the exploitation of disabled people by television companies and charities and poverty which accompanies impairment. The 'Rights not Charity' march of July 1988 was an important example of such kind of demonstration in which despite the enormity of the environmental barriers, the disabled people came forward to the streets for protest against different types of institutional discriminations. The struggling organizations fighting for disability rights altogether formed the British Council of Organization of Disabled People (BCOOP) in 1981. Subsequently in 1985, the Voluntary Organizations for Anti Discrimination Legislation (VOADL), Royal Association for Disablement and Rehabilitation (RADAR) were established to assert the rights of the disabled community. It is worthwhile to mention here that like the American with Disabilities Act (ADA) 1990, the British Disability Discrimination Act (DDA) 1995 (modified in 2005) emerged as a result of disability rights movement occurred in the country and demands made by various disability organizations at different points of time.

In south Asian countries including India, both cultural and structural impediments determine the nature and character of disability. Hence, disability is considered as product of cultural impediments like beliefs and stereotypes as well as structural impediments like poverty, lack of development, illiteracy, unemployment and caste, class and gender barriers and reflected in the basic struggle for survival and cultural understanding (Mehrotra, 2011). Therefore, welfare and rehabilitation under certain schemes were the main focus of the government for the marginalized sections including persons with disability. Besides, the complexity and diversity associated with

the issue of disability makes it a more complex one. According to Nilika Mehrotra, Disability cuts across race, caste and class divisions and therefore the likelihood of framing groups was not a simple possibility (Mehrotra, 2011). More than seventy percent of the disabled live in rural areas where there is virtually no information about rights. In this backdrop the disability rights movement in India was started in the early 1990s and the launch of Asian and Pacific Decade of Disabled persons in 1993 provided a momentum to the movement. Seminars and conferences were also organized in different parts of the country for a comprehensive legislation to protect the rights of the persons with disability. It was in the year 1995; the crucial legislation viz. the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 (PWD Act) was passed by Indian parliament. However, it is worthwhile to mention here that in India, there was a shift at the policy level from welfare to development where disabled people were not only considered as recipient but also a participant of the whole process of development. The conceptualization of social model of disability and emergence of various disability rights movements of different parts of the world influenced Indian Government for this shift from rehabilitation to participation. The Decade of Disabled Persons (1983-1992) marked another shift in the whole debate about the goals of rehabilitation (Mehrotra, 2011). As regards the organizational structure of disability rights movement in India three parallel tendencies were found right from the 1980s onwards (Malhotra,2001). Among these, one group is individual-centred organizations led by educated disabled professionals, largely urban-based, lobbying for provision of services, awareness-creation and dissemination of information. Then there are NGOs managed by both disabled and regular activists largely working through community rehabilitation programmes among rural and urban poor. The third group is of disability studies scholars largely engaged in knowledge production within universities, research institutions and also NGOs (Malhotra, 2001). The first category of groups is basically an advocacy level group which speaks for the rights and network and lobby for influencing at the policy level. They are very much influenced by the events take place at international level and international exchange and collaboration have made them aware of the struggle of people with disabilities in other countries (Daal,2002). The Disability Rights Group (DRG) was such group of likeminded persons with disabilities, who came together in 1994 and lobbied for

legislation for the protection of disability rights. Similarly, National Centre for Promotion of Employment for Disabled People (NCPEDP) is a Delhi based group, which has been using the PWD Act as a reference point and arguing for the better implementation of the Act like 3% job reservation for the disabled, accessible facilities in all public places such as introduction of disability friendly public vehicles in Delhi or even disability friendly toilets in Delhi Railway stations etc. this type of groups uses the methods like hunger strike, dharnas, sit-ins and protests to make the voices of the disabled heard. It is noteworthy to mention here that some lawyers are also active in disability rights movement in India. For example, in the Mandal case (Indra Sawhney vs Union of India, AIR 1993 SC 477), the advocate S K Rungta intervened in the Supreme Court of India for the National Federation of the Blind on behalf of all persons with disabilities to consider the specific issue of whether “backward classes of citizen” as defined by the constitution could include persons with disabilities. However, the apex court allowed for affirmative action for the persons with disabilities under article 14 of the Indian constitution instead of putting them under article 15 and 16 of Indian constitution as “backward classes of citizen” (Pandey et al 2005). The second model of disability rights movement is mainly led by nongovernmental organizations (NGOs). Both in rural and urban areas, the NGOs are promoting organizations of disabled people and parents at local levels. In the last two decades, community-based rehabilitation (CBR) programmes with the support from government as well as international agencies (like World Bank, WHO etc) have been trying to intervene in the disability sector (Miles, 2002). The third model of disability movement in India is the role of academia. However, fewer inputs have coming from academia which could enrich the movement. Anita Ghai, one of the leading activists and academician in the disability sector shows her concern that disability movement has promoted sweeping generalizations about disability and handicap without regard to differences in kind and degree of impairment, or different adaptations to impairment. She also mentions about the dearth of literatures reflecting the social model of disability (Ghai,2003). Most of the literatures available are either in the form of news, reviews, studies in the form of cases and literatures produced by the NGOs or anecdotes by the disability activists to describe some particular incidents (Mehrotra, 2006). However, scholars like Anita Ghai, Renu Addlakha, Nilika Mehtrotra, Nandini Ghosh, G.N.Karna etc have tried to explore

different dynamics of the issue of disability in their research work. The introduction of the disability studies as a separate department in different universities of India is also an important step in bringing consciousness about the issue of disability at societal level.

1.5 State's Responsibility Towards Disability: Exploring the Linkages

In a given society State is the most comprehensive, omnipotent institution that directly or indirectly influences almost every walk of human life. Irrespective of its kind state always plays a very significant role in maintaining stability, order, peace and security in the society. At times, it has been criticized from different perspectives. While, the liberalists call it as a necessary evil, Marxists criticize state as the class institution and present humanitarianists argue for a state with a human face. Despite differences state derives its legitimacy throughout the ages because of its image as a security provider, care giver and as an institution of protection and welfare to its larger section. It is seen that most of the western liberal states adopted welfare model in the inter war period in order to cope up with the economic crisis of 1930s (Swaminathan, 1996, Pp 60-75). State under welfarism is believed to play an active role in the protection and promotion of economic and social wellbeing of its citizens (Blau,1989, Pp.26-31). Welfare state claims to ensure equality of opportunity, equitable distribution of wealth, and public responsibility for those unable to avail themselves of the minimal provisions for a good life (Myles & Quadagno, 2002, 32-35) including adequate food, clothing and shelter. However, disability as an issue of state intervention assumes its significance in a much later period of human history. Needless to say that the two world wars occurred in the first half of the last century was of course a serious humanitarian crisis for mankind. The holocaust created by the world wars also generated large section of disabled people in different parts of the world. Ironically, the issue of welfare state got consolidated in order to mitigate the devastations created by the world wars. Hence, disability as a welfare issue attained a certain degree of importance at policy level. Furthermore, after Second World War with the process of decolonization, developmental state became popular mainly in the post-colonial countries. The government under developmental state pursues a series of policies, including tariff

protection, subsidies and other types of controls aiming at developing selected productive sectors of economic activity (Caldentey, 2009, p.1). Through the creation of an alliance between politics and the economy, a specialized bureaucratic apparatus is also established under developmental state with ample power to coordinate the developmental efforts. It is worth noting that up to 1970s particularly in the East Asian and Latin American countries, for the promotion of industrialization the State intervened in a number of areas and indeed made use of fiscal, exchange rate, monetary, and sectoral policies. In this period of the formation of developmental state, direct intervention was made in the economy, planning and welfare sector. However, disability as a separate issue got less significance in the agenda of developmental state. With the acceleration of globalization from 1980s onwards in the name of integrating global economy much emphasis was given on free market economy and state's role has been minimized as a facilitator to it. Gradually, the global neo-liberal policies have created a regime where the role of the State has been diminishing as a care giver or service provider. On the other hand, the discourses propagated by various international organizations including UNO from 1980s onwards for pro-active role of the State for the cause of human development and security and state's intervention in various humanitarian crises which paved the way for theorization of a liberal humanitarian state (See for detail, UNDP Report 1994). The concept of human development includes human health, literacy rate along with income to broaden the horizon of development (Definition by HDI, UNDP Report 1994). Similarly, human security also encompasses the issue of health security along with other issues where the challenges like disease, disability and death are considered as serious threats to human health. Hence, these discourses include disability as a serious issue of humanitarian intervention. Subsequently, a number of disability movements have been witnessed in different parts of the world particularly from 1990s onwards. These developments led to the enactment of a number of anti-discriminatory legislation in different parts of the world like the Americans with Disabilities Act 1990 (ADA,1990), British Disability Discrimination Act 1995, Persons with Disability Act in India 1995 etc.

1.6 Disability and Rehabilitation:

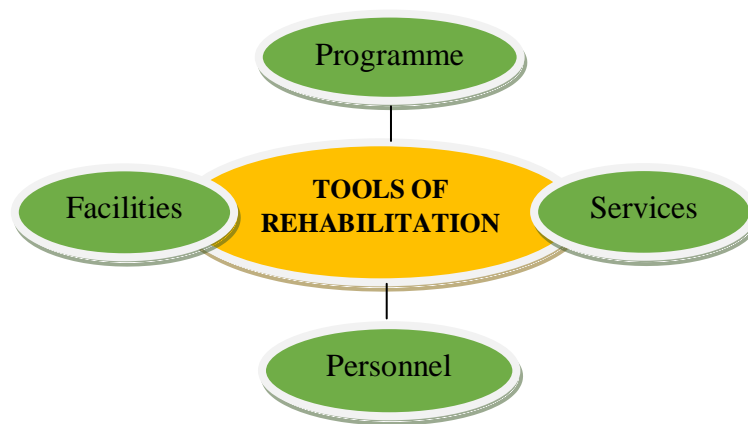
With the broadening of the horizon of the issue of disability from medical model to the social model, it is not only confined as a medical subject where a disabled person is always regarded as a patient in need of medical intervention. The process of rehabilitation has also become wider with the emergence of social model of disability. Generally, rehabilitation refers to the combined and coordinated use of medical, social, educational and vocational measures for training or retraining the individual to the highest level of functional ability (Mani,1998: p. 86). The United Kingdom National Council on Rehabilitation in 1942 defined rehabilitation as: restoration of the handicapped to the fullest physical, mental, social and vocational capable (National Council on Rehabilitation, 1944: p.6). Generally, the process of rehabilitation tries to achieve and maintain optimal functioning in interaction with the environment, using the following broad outcome (WHO, 2011: p.97):

- Prevention of the loss of function
- Slowing the rate of loss of function
- Compensation for lost function
- Maintenance of current function

Realizing the role of rehabilitation process in mainstreaming the disabled people Article 26, Habilitation and Rehabilitation, of the UNCRPD calls for:

“..... appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life” (UNCRPD, 2008). Similarly, The World Report on Disability defines rehabilitation as “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments” (World Health Organization, 2011: p 95). Hence, rehabilitation can be considered as a goal –oriented and time limited process aimed at enabling an impaired person by providing him/her with some tools to reach an optimal mental,

physical and /or functional level. The tools of rehabilitation can be shown in the following diagram (Mani, 1998: Pp.25-28).



1. Programmes include establishment of services, information and publicity, Co-ordination of activities, professional exchange of ideas, fund-raising plans, research/education plans.
2. Services of rehabilitation include physiotherapy, occupational therapy, speech and hearing therapy, counseling, vocational training and placement, prosthetic service, medical treatment and institutional nursing, sheltered employment and work evaluation, recreational services and follow up.
3. Personnel: The people those who engage in the process of rehabilitation are considered as personnel. Physicians and surgeons, physiotherapist, occupational therapist, speech and hearing therapist, social workers and members of voluntary organizations are regarded as personnel.
4. Facilities: Facilities include hospitals, rehabilitation institutes or centres, vocational training schools and schools of particular disabilities.

Broadly, rehabilitation can be categorized into two forms: 1. Community Based Rehabilitation. 2. Institution-based Rehabilitation

1. **Community based Rehabilitation:** In Community based rehabilitation (CBR hereinafter) for all round development as well as care for the disabled people

community takes the responsibility. CBR is a very inclusive and participatory approach where families, neighbourhood, peer groups, voluntary organizations and other institutions together involve in the process of rehabilitation. It does not require experts, buildings, equipments etc. for rehabilitation. It is noteworthy to mention here that in developing countries as institutional based rehabilitation with some institutions and deployment of specialized manpower is not enough to fulfill the goals of rehabilitation to the fullest extent, CBR can be considered as an effective measure. Keeping this point in mind, in the year 1976 WHO drafted a manual of instructions for family members of the disabled individuals and local community leaders which contains detailed instructions for preparing simple aids and appliances with locally available materials, administration of simple therapy and other stimulation methods to handicapped children, and more importantly, creation of confidence in the family to handle its disabled children (Debi, 2017:p.153).

2. **Institution-Based Rehabilitation:** In Institution Based Rehabilitation (IBR hereinafter) process specialized institutions in disability sector under the aegis of the Central and the state governments participate in the rehabilitation process. IBR involves huge expenditure and expert manpower in disability sector. In this process, the family members of the disabled people are not engaged in the rehabilitation process. In India, National Institute for the Visually Handicapped, Dehradun, National Institute for Blind, Artificial Limbs Manufacturing Corporation of India, Kanpur, National Institute of Rehabilitation, Training and Research, Cuttack, National Institute for the Orthopedically Handicapped, Calcutta, Ali Yavar Jung National Institute of Hearing Handicapped, Mumbai are some recognized institutes working for the rehabilitation of disabled people.

1.7: Citizenship and Disability:

The notion of citizenship is an important mechanism to determine the relation between state and individual as well as individual and society through a person participates in the affairs of a state. Hence, it determines the condition for full

membership and inclusion in a society (Singh and Kachap, 2008), where it urges for equality between citizens and in the way in which the state operates in relation to the individuals (Barnes. et al, 2002). Marshall describes citizenship as a multifaceted concept comprising three kinds of rights: civil, political and social. Civil and political rights are essential to ensure justice and participation in the exercise of power in the governance of one's own community. On the other hand, when civil and political citizenship is threatened due to certain social structures and inequalities 'social citizenship' tries to respond to it (Marshall, 1950). It is worth noting that whenever the relationship between State and its population is in crisis, citizenship is the device through which such crises are resolved. In the nineteenth and first half of the twentieth century, such crises were resolved through the extension of adult suffrage to growing number of political citizens (Karna, 2001). Again, in the post-Second World War era, the setting up of welfare state and its consequent emergence of social citizenship signified the occurrence of another crisis between state and its population (Oliver, 1996). In this backdrop, certain issues should be kept in mind while understanding the deeper complexities of citizenship and disability. The concept disability should be redefined from a broader horizon and it should not consider only as a matter of medical approach or personal tragedy. During the late nineteenth century, the philosophers and social theorists applied the concept of citizenship to address the issue of political integration of disabled/ disadvantaged. Of late, the idea of citizenship has not only applied to consider the social integration of the majority into society but also as a criterion to assess the extent to which certain groups were left socially unintegrated/ or excluded (Karna, 2001). In this context, Hudson clearly pointed out two types of rights viz. claim rights and moral rights. Whereas the claim rights are related to the areas of routine discrimination in respect of employment, accommodation, access to leisure and other facilities; the moral rights are associated with the fundamental discrimination in terms of denial of basic human rights to mentally retarded and disabled individuals- such as right to life, procreation and parenting (Hudson, 1988). As stated earlier, definitions of disability and the idea of normality/abnormality vary from place to place based on the public perception of the disabled individuals. Besides, the factors like assertion of private accumulation, the dismantling of the welfare state, the demise of local democracy, the growth of nationalism, the question of European integration,

growing importance of globalization etc. have brought the topic of citizenship at the forefront of the political agenda of modern democratic societies (Held, 1991). Although citizenship is a contentious issue, precisely citizen means to be able to participate in the decisions which create or recreate the societal contours and to be able to take part in key functions- such as work, leisure, political debate, travel and religious observance (Barbalet, 1988). Theoretically, persons with disabilities are entitled to all the rights for becoming a citizen. Nevertheless, in practice due to the existing socio-political structures the situation becomes quite contrary. Generally, universal adult franchise grants political rights to all the people of a nation including right to vote, right to contest, right to take part in elections. However, some of the disabled people cannot exercise their political choices through ballot box or electronic voting machine (EVM). In some cases, even the names of the disabled people are not figured in the electoral register. Furthermore, because of problem of access; access to polling stations, access to transportation or access to information, the persons with disabilities deny their political choices and rights. The postal or proxy voting system are not in a position to resolve this issue because of complex and confounding nature of these systems. For example, these systems involve voting or making decisions before everybody else, which may consider as a mockery of the political process. Apart from voting, due to some other issues, participation in the political process becomes problematic for the persons with disabilities. Mostly, local political parties organize their meetings in such areas which are not accessible for the persons with disabilities. Special attentions are not given to the disabled people throughout the campaign process. For instance, there is no option to make the political information accessible to the hearing-impaired people or visually challenged persons as no provision is there for sign language for hearing impaired or Braille system for visually challenged people. As mentioned earlier, social citizenship is a part of broader concept of citizenship which includes certain social rights like; to use social facilities like others and to have a standard of living or life style in keeping with current societal expectations and so on (Marshall, 1950). However, disabled people cannot enjoy the same social rights or use the public facilities compared to their able-bodied counterpart. The benefits of welfare schemes get into hardly five percent disabled in the urban areas and two percent in rural areas (Karna, 2001). Besides, there

is dearth of special schemes by the Government which can only fulfill the needs of disabled people.

1.8 Statement of the problem:

The present work has made an attempt to study the functioning of different disability related institutions and organizations in the state of Assam. In fact, all kinds of constitutional provisions and legal set up necessarily require an institutional arrangement for their effective implementation in the greater society. With the enactment of different legislations and policies pertinent to disability, a number of institutions have been set up both at the national and the state level. Besides, establishment of non-governmental organizations are also encouraged to work for the persons with disabilities in order to deal with the issue of disability in a more comprehensive and effective way. According to the Census 2011, the total number of disabled persons in the state of Assam is 4, 80,065. The same report shows that 53.6% are male population and 46.4% are female population. Further, 86.5% of the disabled are in rural areas and only 13.5% are in urban areas. The present research is mainly an empirical investigation to study the functioning of both government institutions and non-government organizations to mitigate the issue of disability in the state of Assam locating the issue within the theoretical and empirical framework of State and the issue of disability.

1.9 Objective of the Study:

To examine the role of the State in the field of disability in general and institutions related to disability in particular.

The principle of State legitimacy is directly linked to the activities of the State that provides services to its people. In modern society, State is expected to play a proactive role to ensure social justice based on the principle of distributive justice by

treating equals equally and inequals unequally. Disability is of course one of the most vulnerable areas that requires a more vital role of the State towards building a just and humane society. The State performs its role as a rational political institution through its bureaucratic regimes and makes necessary institutional arrangements to meet the needs of its targeted groups. Hence, to examine the role of the State in the field of disability, it is essential to understand the functions of the institutions pertinent to disability directly linked to the State and non-governmental organizations directly or indirectly supported by the institution of State.

1.10: Basic Research Question:

To see whether State as a rational political institution has a role to play in the domain of disability or not.

The fundamental objective of the State in a given society is to govern its population. Disabled people living within the territorial boundary of a modern state are of course an inalienable portion of the population that necessitates specific attention on the part of the state. At times, the state uses different techniques for governing its population by formulating certain policies or by making needful institutional arrangements. In that sense, for governing disabled populations, state certainly adopts some specific welfare programmes and policies or sometimes takes some initiatives for affirmative action for those populations.

1.11 Significance of the Study:

Disability is a very common phenomenon in all human societies. However, it assumes less significance both in the academic as well as in the public domain. In contemporary time, with the emergence of different disability movements in various parts of the globe, the issue of disability has become a right orientated discourse rather than a matter of welfare and charity. At times, a set of institutional arrangements has been made to address these issues both at the national and international level. In such a situation, it is very much important to understand the functioning of the institutions of

disability, because in a human society it is the institutions through which the social goals and aspirations are materialized. As the present study will mainly focus on the functioning of the disability institutions in Assam, it will certainly be a significant study in the field disability and can provide necessary inputs and insights in formulating policies in future.

1.12 Review of Literature:

While exploring the role of the State in the issue of disability, other aspects associated with disability like rights, rehabilitation, social justice, laws, media, psychology, gender, education, health and so on need to be taken into consideration. Therefore, the literature review relating to the study can be represented in some thematic order viz., Conceptual and Theoretical Understanding of Disability, Disability and law, Disability rights, Gender and Disability, Disability and Rehabilitation, Disability and media.

1.12.1: Conceptual and Theoretical Understanding of Disability:

Conceptual and theoretical understanding of disability encompass holistic study of the issue. It not only tries to define disability both from medical and social model, but also explores other socio-economic and cultural implications associated with it.

Anita Ghai's book *Rethinking Disability in India* (Ghai, 2015) has tried to explore disability as social, cultural and political phenomenon and the difference is as a part of diversity rather than clinical, medical or therapeutic dimension. Citing her personal experience, the author has tried to cross-examine the various forms of oppression and multiple issues of identifications faced by the disabled people.

Tom Shakespeare's book, *Disability: The Basics* (Shakespeare, 2017) has emphasized on the prolonged gaps and barriers in social responses to the challenge of disability by citing some lived experiences of disabled people. As a basic handbook of disability, the book may be an appropriate text book for the students of disability studies as well as students taking a disability module as part of a wider course within social work, health care, sociology, nursing, policy and media studies.

Another book written by Tom Shakespeare, *Disability Rights and Wrong Revisited*, (Shakespeare, 2013) is a comprehensive work to understand disability from a pluralist dimension. The author has pointed out the growing activism of disability movement and research in the last forty years and also opined that to explore the deeper complexities of disability studies, a firm conceptual and empirical footing is needed.

Renu Addlakha's edited book *Disability Studies in India: Global Discourses, Local Realities* (2011) has endeavored to initiate an academic discourse of disability studies in India by exploring various dimensions of the issue of disability. The book has also tried to understand the impact of various social determinants like gender, class, caste, ethnicity etc. on disability. In a country like India, rural-urban disparity is an important factor in accessing knowledge and other services. The book has also tried to address the rural-urban dimension of care, facility and other issues related with disability.

The edited volume *Disability and Society: A Reader* (Addlakha, 2009) has brought in the recent disability literatures of the west to the readers of the Asian countries. The recent disability literatures developed in the west emphasize on the social model of disability. Narratives and life histories of disabled people themselves have a fundamental position in the present-day Disability Studies literature. According to the editors, in the Asian countries, studies conducted in the field of disability are confined only to measure the extent of need or impact of services or attitude to disabled people. Personal narratives, life experiences and insiders' views are lacking in recent entries in Asian countries.

The edited volume *Disability in the Global South: The Critical Handbook* by Shaun Grech and Karen Soldatic (Grech and Karen, 2016) is a comprehensive text on disability issues in the global south. Influenced by decolonizing approaches, the contributors try to portray lived and embodied experience of disabled people, families and communities through contextual, cultural, spatial, racial, economic, identity and geopolitical complexities and heterogeneities. Issues like neoliberal globalization, war and conflicts, structural barriers of redistribution and realization of rights, process of disability representation, and the interstices of gender, ethnicity, space and religion etc.

are also discussed in the book. Furthermore, the book also highlights two models of disability as well as interrelationship between disability, poverty and livelihood both in the urban and rural contexts.

The book *The Oxford Handbook of Disability History* edited by Michael Rembis, Catherine Kudlick and Kim E. Nielsen (Rembis, Catherine and Nielsen, 2018) has tried to define the fundamental issues like identity, community, citizenship, normality etc relating with disability. The basic argument of the book is that disabled people should not live their life just as a care-seeker or patients, but with full dignity as an individual. Themes like disability and cultural construct, disability social movements, social history of medicine, historicizing disability, institutions of disability and so on are covered by the book.

Geetanjali Debi's book *Reflections on Physical Disabilities: A March Towards Emancipation & Empowerment* (Debi, 2017) has tried to explore the various dimensions of disability and the national and international endeavours in the field of it. The book has also analyzed the role of judiciary for emancipation and empowerment of disabled people.

In the book *Disability*, Colin Barnes and Geof Mercer (2003) make an attempt to explore disability from a comparative and interdisciplinary perspective. They explore the evolution of the discourse of disability and provide a wide-ranging critique of academic policy and professional outlook. The authors try to portray disability as a distinctive form of social subjugation common to the experiences of women hood, minority and racial groups.

The book *New Politics of Disablement* (Oliver and Barnes, 2012) reflects the current waves of debate on disability and gradual cuts in public funds with the emergence of global financial crisis. It also includes certain theoretical issues that developed in the recent past on disability and social upheavals connected to the discourses of disability in globalizing capitalist world.

Simi Linton's book *Claiming Disability: Knowledge and Identity* (Linton,1998) is one of the earliest comprehensive volume of disability studies as a field of enquiry.

The book encompasses a broad horizon of issues started from public transportation, education to social impact of disability particularly in the context of western world. The author has explored the division that the society creates like the normal versus pathological, the competent citizen versus ward of the state etc.

The book *Disability Studies in India: Retrospects and Prospects* written by G.N. Karna (2001) has argued for the need of disability research in India. According to the author, in recent times in the field of disability, rehabilitative and medical model has been replaced by social and rights-based model. All together in the western countries disability issue has become a major area of academic discourse too. However, India having the highest disabled population in the world is lagging behind. Therefore, the author has tried to provide a basic understanding of the issue of disability and also to explore different areas of research in India.

The book *Disability and Welfare State in Britain: Changes in Perception and Policy*, (Hampton,2016) has tried to provide a critical illustration of British welfare policies which were created during and after the second World War. The author took a period i.e., 1948-79 for his analysis.

The book *Interrogating Disability in India: Theory and Practice (Dynamics of Asian Development)* (Ghosh, 2016) has discussed disability as a multifaceted concept and also tried to bring to the vanguard the unexplored issues of academic discourse. By putting the theoretical dimensions of disability in South Asia, the book has explored them in Indian context. The book also highlights the gap between theory and lived reality and also between theory and practice.

The edited volume by Gerald Hales, *Beyond Disability: Towards an Enabling Society* (Hales, 2006) is a compilation of seventeen articles which encompasses different dimensions of the issue of disability including care, rehabilitation, reasonable accommodation etc. The main focus of the articles of the book is to unearth various societal obstacles for the disabled people.

The edited volume, *Keywords of Disability Studies* by Rachel Adams, Benjamin Reiss and David Serlin (Adams, Reiss and Serlin, 2015) is consisted of certain

conceptual framework of disability studies for readers and practitioners in the field and beyond. The debates over the issues like prenatal testing, euthanasia, accessibility in public transport and the workplace, post-traumatic stress, the questions about the beginning and end of life etc. are also covered by the book. The book concludes that although disability is an embodied condition, some social, political, historical and cultural dimensions are deeply connected with it.

Sharon n Barnartt's book *Disability as a Fluid State* argues disability as a dynamic phenomenon and the relationship between impairment (physical state) and disability cannot be fixed or permanent. The author also states that because of the complexity within the issue, the nature of disability cannot be predicted. Relating the issue of disability with social, cultural and historical context, the book tries to redefine it and unearth various social and cultural dimensions both at the micro and in the macro level.

1.12.2: Disability and Law:

To understand the legal status of disability, it is essential to examine the legal provisions pertinent to disability both from national and international context.

In the book *The Future of Disability Law in India*, Jayna Kothari (Kothari,2011) has tried to provide an overview of various legal approaches in addressing disability and explore the evolution of disability laws in India. The book has made a critical and comprehensive analysis of the Persons with Disability Act 1995 and also tried to make a roadmap of future of disability laws in India. By comparing Indian disability law with international jurisprudence, the book has attempted to provide an international standpoint of disability and its implications in Indian legislations.

R. Raturi and M. Iyer have made a detailed analysis of a large number of cases of Apex courts and High Courts in their book *Disability and the Law* (Rathuri R. and M.Iyer, 2011). The cases discussed in the book contain rights of the disabled persons in areas of education, accessibility, social security and employment. However, the author concluded that the judgements of the different cases reveal the undaunted attitude of the

government in creating a barrier free environment and implementing disability legislations as well as policies.

The book *Disability and Equality Law* edited by Elizabeth F.Emens and Michael Ashlay Stein (Emens and Ashlay, 2013) is a collection of articles covering some vital issues of disability like the central problem of defining disability and impairment; the dilemma of same versus different treatment; the balance between autonomy and external influence and support, linkages of disability with other anti-discrimination categories such as race and sex; the place of disability theory within identity politics; issue of life, death and our most intimate relationship. The volume tries to analyze these issues locating them in the theoretical paradigm of social model of disability.

The book *International Disability Law: A Practical Approach to the United Nations Convention on the Rights of Persons with Disabilities* by Coomara Pyaneandee (Pyaneandee, 2018) has made a detailed analysis of different international treaties and conventions pertinent to the issue of disability and more specifically UNCRPD. The book has specifically mentioned the obligations of the State parties under UNCRPD and other international treaties while addressing the issue of disability. However, the book has overlooked different socio-cultural connotations associated with the issue of disability depending upon the nature of a State or of a society.

1.12.3: Disability Rights:

Rights are those apparatuses of the state through which an individual or group can lead a dignified life and create a congenial environment for the development of individual personality and a sustainable society. In this context, reference can be made to both positive (entitlement) as well as negative (claim) rights. As disabled persons are one of the marginalized sections of the society, their rights need to be understood while exploring the role of the state in this regard.

The edited volume *Human Rights and Disability Advocacy* (Sabatello and Schulz, 2013) has tried to provide a critical insight of the Convention on the Rights of

the Persons with Disabilities (CRPD), which came into force in 2008 including contents and purposes of the convention. Shifting from the medical model of disability, the convention argues that the issue of disability is a social edifice, caused by environmental and attitudinal barriers towards persons with certain impairments. The convention further reinforced the need of “reasonable accommodation” and “respect for difference” while implementing the treaty. However, no legal analysis of the provisions of the convention is found in the book.

The edited volume titled *Disability Rights* by Peter Blanck (Blanck, 2017) is a compilation of twenty-five articles where the main focus is to explore various socio-economic and cultural causes for the discrimination of the persons with disabilities. By comparing disability legislations and policies various countries of the world, the book has also tried to explore different issues and concerns to improve the status of the persons with disabilities and protection of basic human rights of them. Although the book has overlooked the diverse societal and cultural contexts of different countries of the world, it can be considered as an inclusive text for understanding disability rights at global level.

The book *Disability, Citizenship and Social Exclusion* (Singh and Kachap, 2008) is an edited volume that includes a number of essays that try to connect the issue of disability with the question of citizenship, social exclusion, development and human rights etc. The book is intended to debate all these pertinent issues of disability particularly in the context of India. The main focus of the book is to provide a new impetus for all concern to provide the person with disability, their dignity and fundamental rights.

In the book *Rights of the Persons with Disability in India*, Rumi Ahmed (Ahmed, 2015) has critically analyzed the existing disability laws in India, including the PWD Act of 1994 with the help of some major judicial verdicts. The author has mentioned that as regards disability legislations, India is lagging behind because there is no comprehensive legislation since the publication of the book which includes the social model of disability and the new wave of human rights model which are incorporated in the United Nations Convention on the persons with Disability (UNCRPD).

The book *Disability Rights and Awareness* by Justin Healey (Healey, 2010) has revealed the fact that although a significant portion of population in Australia has disability i.e, one in every five persons, the legislations or various schemes of the government are not adequate enough to fulfill the need and expectations of this population. The author has tried to provide critical overview of major disability groups viz. physical, intellectual, psychiatric, sensory, neurological working in their respective fields. Exploring the various instances of disability discriminations, the author also explored various causes of discrimination faced by people with disability and possible ways for the protection of rights of the persons with disability.

1.12.4 Disability and Rehabilitation:

Rehabilitation of the disabled persons is an important aspect of disability. When medical model fails to cure a particular type of impairment, rehabilitation is the only way through which the disabled people are being mainstreamed in the society. Hence, any work on disability cannot bypass the issue of rehabilitation.

Sikha Dhawan's book *Handbook of Disability and Rehabilitation* (Dhawan,2011) is a comprehensive text to understand the issue of disability both from medical and social model including the detailed analysis of various policies and programmes for the protection and promotion of disability rights at the national and international level. For example, in Indian context both constitutional and statutory provisions for the protection of disability are mentioned in the book. However, the author has not provided the critical dimension of the policies and programmes and their future implications.

The book *Perspective on Disability and Rehabilitation: Contesting Assumptions, Challenging Practice* (Hammell, 2006) reflects issues pertinent to rehabilitation, bodily disablement and the idea of self-sufficiency of persons with disability etc. It also explores certain theoretical ideas and realities of everyday life of persons with disability.

In their book *Human Disabilities: Challenges for their Rehabilitation* Keya Sengupta, Rakhal Kumar Purkayastha and Digvijoy Nath Pandey (Sengupta et al, 2000) have analyzed different challenges in the rehabilitation process of the disabled persons. Issues like different rights of the disabled persons, role of the NGOs in prevention, early intervention and rehabilitation of the disabled persons, role of educational institutions and corporate sectors etc. are also critically discussed in the book.

Prithpal Kaur's book *Critical Analysis of the Disabled Persons (Problems and Solutions)*, (Kaur,2010) has tried to explore various dimensions for equal opportunities and rights for the persons with disability. By giving a critical analysis of the constitutional and statutory provisions regarding disability, the book has also tried to explore the problems associated with the rehabilitation process of the disabled persons. Citing own personal experience with disability, the author has tried to endow with certain solutions to the problems faced by disabled people in their day-to-day life.

1.12.5 Gender and Disability:

Gender analysis is an important part of any kind of social or emancipatory discourses. Gender is the power relationship based on perceived differences between male and female, determined by the structures and institutions of a society. Generally, women are discriminated due to gender bias but disabled women face multiple discriminations by being both women and disabled.

Nilika Mehrotra's book *Disability, Gender and State Policy: Exploring Margins* (Mehrotra, 2013) has tried to understand disability from an anthropological perspective. The book has tried to explore the cultural perceptions of disability in India, the construction of gender and personhood in rural and urban contexts, and the issues in social support and care work. The book also accentuates disabled persons' access to resources like education and employment opportunities in diverse sectors and its psycho social impact on poor urban women.

In their book, *Women with Disabilities: Essays in Psychology, Culture and Politics* Michelle Fine and Andrienne Asch (Fine and Asch, 1988) have argued that in the societal level, the image of a women as a care giver is a significant component of

normative construction of femininity. However, a woman with disability is herself in need of care which led her to a devalued status of social hierarchy and locates the women of disability in a life of a social isolation. Generally, a man with disability does not become victim of such rolelessness. The authors further stated that as gender is being socially constructed from the biological difference between male and female, disability is also constructed from the biological difference persons with disability and non-disabled persons.

Anita Ghai's work "*Disabled Women: An Excluded Agenda of Indian Feminism*," (Ghai, 2002) has explained the relationship between normal body and the issue of femininity in a given society. The author has mentioned disabled female body as rejected body as she is unable to accomplish the sexual assignments, needs and desires of a normal body and she herself is in need of care. In this regard the author has cited examples from various mythological narratives. For instance, in Ramayana, Lakshmana, brother of lord Rama, cuts off the nose of Shurpanakha, sister of king Ravana, who shows interest in him. By doing this, Lakshmana made her an 'ugly female' and also proved that how disability and de-sexing are equated in the Indian psyche.

In the work "*Embodied Experiences: Being Female and Disabled*" Nandini Ghosh (Ghosh, 2010) has contextualized gender identity with day-to-day live experience of a locomotor disabled woman in Bengal. The author has argued that in Bengal the gender identity was basically evolved and accepted during the period of nationalist struggle, where the picture of a woman was portrayed as mother which was similar with the nation. The same ideology also made a strict distinction between the activities of men and women with the concept of outside (*bahir*) and inside (*ghor*). The activities of practical and material world come under the domain of *bahir* and the *ghor* was conceived to be the representation of one's true identity, one's spiritual self where woman was the part of it. However, the author argues that due to their deformed body and physical limitations to perform even the day-to-day activities, women with disabilities are excluded from this normal type gender construction and not considered as "Bhalo Maye" (Good Woman) in the societies of Bengal.

1.12.6 Disability and Media:

In contemporary time, media occupies a significant space in our day-to-day life. How disability is being portrayed through media is of course an important dimension of disability studies. The growth of information technology and digital media provides easy access to information and knowledge. However, all digital devices are not disabled-friendly which led to a limited access to information for disabled persons.

In the book *Restricted Access: Media, Disability and the Politics of Participation*, Elizabeth Ellcessor (Ellcessor, 2016) has explored both the positive and negative aspects of the use of digital media. Now a days with the technological growth dissemination of information and cultural participation has become easier through certain digital media including social networking sites, you tube etc. However, these mechanisms are not suited for persons with disabilities including hearing impaired and visually challenged. After conducting certain interviews with the policy makers and accessibility professionals and ethnographic study of internet use by the persons with disabilities, the author has revealed that the technology only facilitates the participation of those who are already privileged, then its progressive potential remains unrealized. To rethink digital media accessibility for the people with disabilities, the author proposes for the importance of alternate uses, marginalized voices and invisible innovations.

Elizabeth Ellcessor's another book (Ellcessor, 2017) *Disability Media Studies*, has brought in some key ideas and new horizon in the emerging field of disability media studies. The important issues covered by the book are disability representation, the role of media in forming cultural assumptions about ability, the construction of disability via media technologies, and how disabled audiences respond to particular media artifacts. Although the book has not encompassed the politics of media and disability, it tries to provide a comprehensive overview for the scholars of media as well as disability studies.

The edited volume by Katie Ellis, Gerad Goggin, Beth Haller and Rosemary Curtis (Ellis et al., 2020), *The Routledge Companion to Disability and Media*, has tried to explore the complex dynamics of disability and media which are becoming an

important area of contemporary culture and social life. From the time immemorial media (including both print and digital) has been considered as a mirror of the society. In contemporary time in the age of digital technology, media plays a very imperative role in disability transformation which has widespread implications for global societies. Keeping these issues in mind, the book has tried to describe various developments in the field of media and how it portrays disability. It has also covered a wide range of traditional, emergent and future media forms and formats.

1.13 Theoretical Structure

The present study is mainly based on the functioning of institutions pertinent to disability in the state of Assam. As medical intervention is an unavoidable part of disability, most of the institutions established in earlier time are preoccupied with medical model of disability. The level of disability is being measured only with the help of medical intervention for providing any kind of rehabilitative initiative or affirmative action adopted by the State. At the same time, social model provides a deeper insight to understand disability as social issue. In that sense, medical and social model are not contradictory or binary models, rather both are complementary to each other. Hence, both medical and the social model of disability have taken into consideration in understanding the role of the institutions directly or indirectly supported by state towards addressing the issue of disability.

1.14: Methodology

The study is based both on primary and secondary data. Books, journals, periodicals, newspapers, classified websites etc. are the main sources of secondary information. Exploratory method has been carried out for collecting primary information.

For the purpose of the present study, a number of governmental and non-governmental institutions/organizations pertinent to disability are selected that are working in the state of Assam. As medical model plays a predominant role in government legislations like PWD act 1995, the Government Health Department is the prime institution that has been bestowed upon the responsibility in identifying and determining the level of disability of a person. On the other hand, in the state of Assam Social Welfare Department is the Nodal Department through which various welfare schemes are implemented and authorized certificate has been provided to persons with disability to ensure government entitlements and benefits. Hence, to understand the role of the state in disability, various stakeholders of these two government departments, like government officials, doctors and health workers were interviewed with unstructured schedule.

At the same time, office of the State Disability Commissioner is the quasi-judicial authority in the state to ensure justice to the person with disability in case of any discrepancy. Therefore, interview is also carried out with the disability commissioner. A number of non-governmental organizations are also playing a significant role in various issues pertinent to disability in the state of Assam. Hence, these organizations are also taken into consideration for the purpose of the present study. The selection of non-governmental organizations is based on purposive sampling method. Unstructured interview is also be carried out with relevant personalities of those organizations like director, founder, and special instructor and so on.

Apart from these a few scheme beneficiaries are also interviewed to understand the level of implementations of the government policies pertinent to disability. As regards the selection of schemes, two schemes viz. Scheme for Rehabilitation Grant and Scheme for scholarship to the students pursuing technical and medical education are selected for empirical investigation. As rehabilitation model is the one of the important models of the Government to address the issue of disability, therefore Scheme for Rehabilitation Grant was selected. On the other hand, within the disabled people those who are pursuing medical and technical education can be considered as the most empowered category, therefore their opinion on government's schemes is also important to understand the role of the State institutions in addressing the issue of disability. For

the empirical investigation of the present study Kamrup (Metro) and Jorhat Districts were selected. The data available in the Directorate of Social Welfare, Government of Assam shows that the highest number of the selected scheme beneficiaries are found in Kamrup (M) and Jorhat District respectively. The field study was conducted from June 2017 to June 2019 among the total number of the beneficiaries of two sessions viz. 2017-2018 and 2018-2019 respectively of the aforesaid schemes. As regards the selection of NGOs, four NGOs viz., Shishu Sarothi, Ashadeep: A Mental Health Society, Prerona: Spastic Society of Jorhat and Swabalambi are selected for empirical investigation based on purposive sampling.

1.15 Limitations of the Study:

The present study is only confined to examining the role of the State in addressing the issue of disability. To fulfil this purpose, the study covers only the institutional perspective of the State. It does not encompass the analysis of various policies and programmes adopted by the State pertaining to the issue of disability. Besides, the study attempts to investigate the issue of disability as a holistic category rather than specific emphasis on different categories of disability.

CHAPTER II

THE ISSUE OF DISABILITY IN INDIA: THE HISTORY AND POLICY

2.1: Introduction:

The interwar period marked the beginning of welfarism as a dominant ideology in most of the western states at the international level. State under welfarism is believed to play a pro-active role in the protection and promotion of economic and social wellbeing of its citizens. Welfare State claims to ensure equality of opportunity, equitable distribution of wealth, and public responsibility for those unable to avail themselves of the minimal provisions for a good life including adequate food, clothing, shelter and so on. Simultaneously, the issue of disability also gained significance as a policy priority in the social security measures adopted by many western countries because, the devastation and the genocide caused by the World Wars led to the increasing number of disabled persons in many parts of the world. Following the Western model of welfare state, the newly liberated countries of Asia, Africa and Latin America also adopted a welfare model in order to address gross structural problems like poverty, unemployment, lack of infrastructure generated by centuries of colonial exploitation. India also embraced welfarism as the guiding principle after independence. However, disability as a social category has emerged in the political discourses of India only in the recent past. Although the Constitution of India talks of equality before law without any discrimination on the basis of caste, class, religion, creed, gender, ethnicity, place of birth and affirmative action like reservation for deprived categories such as backward class, caste etc., the Constitution was almost silent on the question of disability. Hence, the discourse of social justice in India is much more preoccupied with caste, class, religious minorities, tribes etc and accordingly constitutional and legal arrangements have been made for reasonable accommodation and mainstreaming of those categories in different point of time. Hence, disability as a deprived category has

been an excluded agenda of emancipatory discourses in India for quite a long time. In India the issue of disability assumes significance as a national priority only after the Indo-Pak war of 1971, once government decided to compensate the soldiers who became disabled in 1971 war. After the victory of India in Indo-Pak war of 1971, Mrs. Indira Gandhi, the then prime minister of India made the announcement for the reservation of jobs for the disabled soldiers. Initiatives have been taken under the Ministry of Welfare for preparing papers on the strategies for comprehensive development of programmes, services and opportunities for persons with disabilities. Subsequently, the Government of India also announced a national plan in 1981 for the all-round development of persons with disabilities and these developments played a significant role towards the enactment of Persons with Disability Act 1995 (Karna, 231). However, the issue of disability is quite prominent in the complex social milieu of India from time immemorial. The presence of various disabled characters in different mythological narratives signifies the social space and the stigma associated with disability. Hence, to understand disability as a socio-political issue, it is essential to explore the historical evolution of disability as a social imaginary. Therefore, the present chapter makes an attempt to understand how the idea of disability evolves in the complex socio-cultural milieu of India and its journey from a social imaginary to a political category for policy priorities.

2.2 The Issue of Disability in India: Understanding the Socio-cultural

Context:

The depiction of the issue of disability in socio-cultural life of Indian society can be traced back to the time of Ramayana and Mahabharata. There were two opposite dimensions in contextualizing the issue of disability in ancient time. On the one hand, the ancient Indian society was philanthropic in nature having the characteristics like love, compassion and sympathy for the poor and needy and on the other hand there was also the feeling of agony to the people living with certain deformities. The Smritis, Dharmasutras and the Bagvad Gita etc have references of charity and benevolent approach to the needy and disabled persons in the society. As Indian family system is

predominantly joint in nature, it has a strong value system to show respect and care to the aged, sick persons or any handicapped person etc. According to Caraka, a medical scholar in ancient India known for the Caraka Samhita, administration provides care for disabled people (Caraka Samhita 400-200 BCE). Again, it is worthwhile to mention here that the characters having any disability or any deformity during the age of Mahabharata and Ramayana were considered as the source of tribulations in the society (Basham, 1924. Pp.310-311). For example, it is found in the epic Ramayana that because of conspiracy and intervention of Manthara, the maid servant with a hunch Lord Rama and others were sent to exile. Likewise, in Mahabharata, although the blind king Dhritarastra was not directly associated with any evil spirit, but because of his incapability as a king the war of Kurukshetra took place. Shakuni, the maternal uncle of Kaurav's in Mahabharata was the main instigating force for the war of Kurukshetra also a disabled person having a limping leg. However, in certain other mythological narratives, abnormality or supernatural or deviation from the normal behaviour were used to portray some powerful God and Goddess who emerged at certain point of time to save the humanity. For example, Lord Vishnu's appearance as a dwarf (Baman Avatar) or as Narasimha (that is the features of lions and human being together) was to eliminate Rakshas or the evil. Again, it is believed that to kill the demon Asura, Goddess Durga appeared having ten hands because she needed additional strength and power. Besides, according to the Karma Dharma theory of Hinduism disability is nothing but emerges as a result of wrong actions in one's past life or the present one. As Bhatt observes:

The theory of Karma was instrumental in depriving the disabled of their inherent right to lead an independent life. It was believed that the disabled were reaping what they had sowed (sic) in lives bygone and any attempt to ameliorate their lot would, therefore, interfere with the divine justice (Bhatt 1963: 96)

In later period of time when Buddhism emerged as a dominant religious discourse, it was seen that disability was gradually been projected with a more tolerant and benevolent approach emphasizing the virtues of mercy, charity, truth, purity, kindness, goodness and above all non violence (ibid). Buddhist philosophy further stated that along with physical fitness, mental health and hygiene are equally important

to bring health and happiness in human mind. It needs to be mentioned here that during the reign of Chandragupta Maurya, he initiated certain programmes for the vocational rehabilitation of physically, socially and economically handicapped within his kingdom. For instance, Kautilya, the renowned political economist of the Maurya period and author of Arthashastra mentioned that the king should provide the orphans, the aged, the infirm, the afflicted and helpless with maintenance (Shamasastri 1923: p5). Keeping in view the principles of Buddhism, king Ashoka also extended certain philanthropic works like establishment of public health care system, arrangements of medicine, food and drinking water to the needy and disabled people (Smith, 1920:p66). Even during the Mughal period Zakat was initiated to help the needy and disadvantaged people. Zakat is a religious obligation of Muslims according to which an amount of earnings should be contributed to the welfare of the disadvantaged sections of the society. Although, lots of charitable works have been done during the great rulers of Mughal period like Akbar, Shajahan or Aurangzeb, nothing was specially formed or instituted to help the crippled or the disabled. However, Sher Shah who dethroned the Mughal emperor Humayun was well known for his developmental activities and welfare schemes was also one-eyed. But, the efforts to do welfare for the poor crippled or even for the disabled persons by the Mughals were very minimal compared to the amount of time and money that they exerted in the field of art and architecture.

Table 2.1: Sample Survey of Histories of Disablement in India

Events/subjects	Themes/Concepts/Ideas	Project/Intent
Hindu/Buddhist/Islamic traditions---- miracles, blessings, curses	Charitable treatment of deformed persons as part of religious practice	To describe and explain social attitudes to disablement and disabled persons in present times
Ancient and medieval culture and traditions	Deformity as a result of past actions—karma (Miles 2001)(Blessing or curse ?)/ Pity shown to persons with deformities.	To understand theological contexts and the emergence of concepts of charity, institutionalization/segregation and social stigma
Colonial intervention in the form of schools, hospitals and institutions	Social ostracism in the face of religious exclusion of disabled persons Medical texts such as Caraka Samhita-----disease as a result of wrong actions in the past(Bhatt,1963). Caraka Samhita as instance of medical knowledge; evidence of moral model of Hindu practices; prescription of social behavior? Manu’s laws: legal precepts? Religious prescriptions? King Ashoka’s method of vocational rehabilitation: Instance of royal administrative governance method? Instance of religious influence on governance Aurangzeb’s need to hide his weak knee Beginning of formal care and rehabilitation of disabled people. Disruption of the old order of familial care; implementation of segregation of sick and ill persons; methods of modern medicine isolate the person with disease/ disability from community-based care (Arnold 1993;Bhatt1963;Miles 1995)	To explain current reactions to disability in India as a curse or as a shameful feature and study the history of this negative perception to one’s disability being the result of individual fault. India treated its disabled people as faculty and punished or cursed. Colonial modernity reinstated maligned people to charity care and rehabilitation. Present attitudes as a result of traditional fatalistic attitude and superstitious mindset of Indians. India had a glorious past when disabled people were treated with respect; this was disrupted by British rule

(Source: Anand, 2013: Pp.45,46)

During the time of British administration, initially they did not show much concern about the disability issue, in fact the social security measures as a whole. The

reason may be that in the earlier stage, the British Government was busy in putting their foot firmly on the soil of India. However, the British Government passed the Lunatic Asylum Act 1858, which can be considered as the first legislation to deal with the issue of disability specifically for setting up mental asylums and procedural checks for admission and treatment of patients with a view to segregate those who by reason of insanity were troublesome and dangerous for others. Besides, the Indian Penal Code 1860, The Indian Contract Act 1872, The Lepers Act 1898, The Lunacy Act 1912 and so on were also some important legislative initiatives by the British Administration directly or indirectly related to the issue of disability. It is noteworthy to mention here that the inclusion of disabled people in the Census as a part of the population during British administration had made it easy to separate the disabled people from normal individuals of the society. In the schedule called the 'House Register' of first modern census of India in 1872, questions regarding the physically and mentally disabled and persons affected by leprosy were included. This system of data collection was continued till 1931 census. However, in 1941 census the enumeration of disabled population discontinued as the then Census commissioners put doubts regarding the authenticity and the quality of data collected on disabled population (Census on Disability after India's independence will be discussed later). Hence, it can be said that during British administration efforts were only made to identify the disabled people from the mainstream population and consider them as patients. No welfare measures were initiated during the time of British administration for the benefits of the disabled community.

2.3 Constitutional Perspectives on Disability in India:

Understanding the constitutional provisions is important to know the government's initiatives in the field of disability. Although the Constitution of India is based on the principles of social justice and human rights, the term disability does not find any distinctive position in it. The Preamble, the Directive Principles of State Policies, the Fundamental Rights enshrined in the constitution stand testimony to the commitment of the state to its people. These provisions envisage a very positive role for the State in the enhancement of the status of the disadvantageous groups

(Bandhopadhyay: 2011, p.148). During the time of framing of the Indian constitution, only women and children were identified as vulnerable groups who require extra care and security. Aged, disabled, orphans, homeless etc were ignored as marginalized groups who need special legislations and care at that point of time. However, it is imperative to understand various constitutional provisions which try to bring basic equality and justice in the society and which may be considered as base for various legislative measures initiated by the government of India. The preamble of Indian constitution acknowledges in securing all its citizens social, economic and political justice which are intrinsically associated with the concepts like morality, welfare, happiness, liberty and equality. The preamble also promises to provide fraternity assuring dignity of the individual. Again, the fundamental rights were included in the Indian constitution as they are considered vital for the development of personality of every individual and to preserve human dignity. For example, the article 21 of Indian constitution states- no person shall be deprived of his life and personal liberty except according the procedure established by law. According to this principle, each and every person has the right to life with dignity which refers to a life filled with honour and acceptance by the society. It further includes the accessibility in education, employment, health-care etc. It is noteworthy to mention here that in the life of most of the physically disabled persons, many of these concepts are missing and they live a miserable life. Similarly, articles 14, 15 and 16 of the Indian constitution form the cornerstone of the constitutional protection of the rights to equality and non-discrimination in India. Article 14 guarantees equality before the law and equal protection of the laws. Article 15 provides limited protection based on discrimination on the ground like religion, race, caste, sex and place of birth. Article 16 provides for equality of opportunity in caste, sex, descent, place of birth or residence in relation to such employment. Hence, it can be said that although the constitution of India does not specifically prescribe discrimination on the ground of disability, the article 14 and article 15 of the constitution guarantee equality and equal opportunities for all citizens. The constitution of India also guarantees the fundamental right to free and compulsory education for the children up to the age of fourteen years. According to the Right to Education (RTE) Act 2009 (came into force on 1st April, 2010), which is envisaged under article 21-A, every child has a right to full time elementary education of satisfactory and equitable quality in a formal

school which satisfies certain essential norms and standards. The right to education is a universal entitlement to education, recognized in the International covenant on Economic, Social and Cultural Rights as a human right that include ‘the right to free, compulsory primary education for all, an obligation to develop secondary education accessible to all, in particular by the progressive introduction of free higher education. The right to education also includes a responsibility to provide basic education for individuals who have not completed primary education’ (Debi 2017: 101). In addition to these access to education provisions, the right to education encompasses the obligation to rule out discrimination at all levels of the educational system, to set minimum standards and to improve quality of education (www.shareyouressay.com). Apart from these, the Directive Principles of State Policies also provide some directives to the state to bring equality and social justice in the society. The article 41 of the constitution of India directs the state to ensure to the people within the limits of its economic capacity and development-

- a) Employment
- b) Education and
- c) Public assistance in cases of unemployment, old age, sickness and disablement and in other cases of undeserved want (Shukla: p. 305).

It is worthwhile to mention here that the term disablement was found only in article 41 of Indian constitution. The article 41 does not confer a justifiable right, the supreme court has, by its interpretation, bearing in mind the goal of socio-economic, held that the courts should so interpret a statute as will advance the objective underlying Article 41 (Debi 2017: p.105). Apart from Article 41 of Indian Constitution, the other articles under Directive Principles of State Policies like Article 42, Article 45, Article 47 etc also try to bring socio-economic equality in the society. Article 42 instructs the state to undertake efforts to enhance the working conditions of the pregnant women outside home. Article 45 requires the state endeavour to provide, within a period of ten years of the commencement of the constitution, for free and compulsory primary education for all children until they complete the age of fourteen years (Jain 2005:

p137). Article 47 states -----the state shall regard the raising of the level of nutrition and the standard of living of its people and the improvement of public health as among its primary duties and in particular, the state shall endeavour to bring about prohibition of the consumption except for medicinal purpose of intoxicating drinks and of drugs which are injurious to health (Shulka: p.311). As health and wellness is very much related with the issue of disability, the article broadly tries to cover the issues of prevention of disease, rehabilitation and inclusion at different levels, nutrition, communicable and non-communicable diseases, injuries, physical therapy, durable medical treatment, disability and HIV AIDS etc. It is a well known fact and mentioned in the first chapter that poverty and malnutrition are the main causes of disabilities found in developing countries. For example, Vitamin A deficiency may lead to night blindness, Vitamin D deficiency may cause rickets etc. Hence, it can be said that article 47 of Indian constitution is an important inclusion which may directly or indirectly directs the state to control and prevent disability in the society.

The constitutional perspectives amplify two important approaches viz., welfare-based approach and rights-based approach. The welfare-based approach considers the persons with disabilities as objects of the state charity in need of medical treatment and protection. On the other hand, in the right based approach, the persons with disabilities are regarded as citizens with rights, equally capable of claiming these rights and making autonomous decisions based on their free and informed consent as well as being active members of the society.

2.4 Disability Jurisprudence in India: A Historical overview

Disability as a legitimate subject of anti-discrimination legislation gained recognition in 1990s all over the world. The Americans with Disabilities Act 1990, British Disability Discrimination Act 1995 etc were the path breaking legislations in the field of disability. In India the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 is the first comprehensive legislation on disability which is mainly influenced by these two acts and various international events took place at that point of time. However, to address the issue of

disability sometimes as a matter of medical intervention or sometime as a matter of social welfare various legislations were initiated at different point of time. As mentioned earlier the Lunatic Asylum Act 1858 can be considered as the first legislation to deal with the issue of disability specifically for setting up mental asylums and procedural checks for admission and treatment of patients with a view to segregate those who by reason of insanity. The following legislations passed at different point of time are directly or indirectly related to the issue of disability.

- **The Lunacy Act 1912:** The Lunacy Act was introduced by the British Government in the year 1912 to provide institutional care and asylum to the mentally ill people. Before this act came into effect, the Lunatic Asylum Act 1858 (actXXXVI of 1858), the Military Lunatics Act,1877 (Act XI of 1877), The Indian Lunatic Asylum (Amendment) Act, 1889 (Act XX of 1889) etc were enacted by the British administration to look after the issue of mental illness. The section 3 (5) of the Lunacy act 1912 used the term ‘lunatic’ to mean an idiot or person of unsound mind including the issues like schizophrenia. However, in the Mental Health Act 21987 which replaced Lunacy Act 1912, instead of the expression ‘lunatic’, the expression mentally ill person was used (Alexander, 1996: p233). The Lunacy Act 1912 brought the mental hospitals under the jurisdiction of civil surgeons which were earlier under the purview of Inspector General of Prisons. As mentioned earlier the Lunatic Asylum Act 1858 established some asylums to the mental patients which were later replaced by mental hospitals under Lunacy Act of 1912 (Doshi, <http://www.ndcnihfw.org/html/legislations/mentalhealthcareact.html>). The Lunacy act also explained the role of improved techniques of medical and surgical science to understand the cause of mental illness and improved methods of coping with it.
- **The Workmen’s Compensation Act 1923:** The workmen’s compensation Act 1923 imposes an obligation upon the employers to compensate the workers for accidents, occurring during the course of employment, either leading to the death or disablement of the workmen. Considering certain underlying conditions, the act incorporates the provisions

for the compensation to be paid for temporary or permanent disablement or also for total and partial disablement. The conditions which could debar a workman from securing compensation are mentioned below (Padhi, 2011: p.8):

- a) If the injury did not result in total or partial disablement for a period exceeding three days.
- b) If the employer could prove that the workman was drunk or willfully disobeyed the order or direction of the employer or the workman intentionally removed the safety devices.

- **The Employees State Insurance Act:** The Employees State Insurance act was passed on 19th April 1948 to make certain provisions to offer certain benefits to employees in case of sickness, maternity and employment injury. The act identified three types of disability viz., permanent partial disablement, permanent total disablement and temporary disablement.

- a. Permanent partial disablement: According to the Section 2 (15A) of the Employees State Insurance Act, 1948 permanent partial disablement of a person must fulfill the following conditions:

- i. Partial disability must be permanent in nature
- ii. The disability must diminish the earning ability of an employee
- iii. The reduction in the earning capacity must be in the employment which he or she was competent of undertaking at the time of the accident ensuring in the disablement.

- b. Permanent total disablement: The Section 2 (15B) of the act has specifically mentions certain conditions for permanent total disability of a person.

- i. The disablement occurred during the course of employment must be permanent in nature

- ii. The disability must result in incapacitating the employee from all work that he or she was capable of
 - iii. The injuries like loss of both hands, loss of a hand and a foot, very severe facial disfigurement and absolute deafness are considered as permanent disability in the act
 - c. Temporary disablement: Under section 2 (21) of the act, following conditions are considered as the conditions of temporary disability ----
 - i. It must result from an employment injury
 - ii. The injury must necessitate medical treatment
 - iii. The injury must make the employee temporary incapable of discharging the duties
 - iv. The work must be the work that the employee was doing prior to the injury

- **The All-India Services (Special Disability Leave) Regulations Act, 1957:** The section 3 of All India Services (Special Disability Leave) Regulation Act, 1957 lays down special disability leave to a service holder who suffers a disability as a result of risk of office or special risk of office. The Section 2 (1) (a) of the act defines disability as any injury, illness, infirmity or disease. However, leaves on disability ground shall not be granted unless the disability manifested itself within three months of the occurrence to which it is attributed and the member of the service who suffers the disability acted with due promptitude in bringing it to notice of the Government (Debi 2017, p.122).
- **Children Act 1960:** The children act 1960 was passed by union parliament on 26th December, 1960. The act attempts to provide care, protection, maintenance, welfare, training, education and rehabilitation of neglected or delinquent children and for the trial of delinquent children in the union

territories (wcd.nic.in). the Section 47 of the act provides for the transfer of children of unsound mind or suffering from leprosy to an asylum or mental hospital or other place of safe custody for being kept there for the remainder of the term for which he has to be kept in the custody under the orders of competent authority.

- **The Income Tax Act 1961:** The Income Tax Act 1961 provides deduction u/s. 80U in pursuance of which an individual (Indian citizen and foreign national) who is resident of India, and who suffers from not less than 40 percent of any disability is eligible for deduction to the extent of Rs. 75000/- and in case of severe disability to the extent of Rs. 125,000/-. For availing deduction u/s. 80U, the assessee needs to fulfill certain legal formalities like he has to obtain a certificate from medical authority constituted by either the Central or the state Government, along with the return of income for the year for which the deduction is claimed. Deduction for expenses on maintenance or medical treatment (including nursing), training and rehabilitation of a disabled dependent has also included in the act (Section u/s 80 DD).
- **The Medical Termination of Pregnancy Act, 1971:** Medical Termination of Pregnancy Act 1971 was passed by the Union Parliament on 10th August 1971 to provide for the termination of certain pregnancies by registered medical practitioners if any abnormality occurs in the foetus. However, such termination can be conducted only when the duration of the pregnancy is more than 12 weeks and less than 20 weeks. Thus, the act seeks to prevent the birth of children with physical or mental disabilities {Section 3(2) (b) (ii)}.
- **The Mental Health Act 1987:** The Mental Health Act 1987 was passed on 22nd May 1987 (which has replaced the Lunacy Act 1912) to consolidate and amend the law relating to the treatment and care of mentally ill persons, to make better provision with respect to their property and care of mentally ill persons, to make better provision with respect to their property and affairs and for matters connected therewith or incidental thereto. The act provides that any person, not minor, who considers himself to be mentally ill person and desires to be

admitted to any psychiatric hospital for treatment, may request medical officer-in-charge as a voluntary patient (Section 15). If person admitted is to be minor, the request can be made by guardian (Section 16). The Act empowers a police officer to arrest a mentally ill person who is incapable of taking care of himself/herself [Section 23(1)]. After arrest, the police officer is bound to inform without delay about the reason for detaining him/her, if he/she is able to understand. If the person is unable to understand, then the same should be informed to his/her relatives or friends [Section 23(2)]. The mentally ill person taken in protection shall be produced before nearest magistrate within 24 hours [Section 23(3)]. The magistrate can pass appropriate order under the Act (Section 24-36). The mentally ill person has the right of maintenance [Section 25(4) and 79]. There is also provision of manager or guardian appointed by the Court to take care of the property owned by a mentally ill person, if he/she is not in a position to do the same (Section 62 and 63). Chapter VIII of Act mentions about the protection of human rights of the mentally ill person. As the act only provides for the guardianship and institutionalization for the persons with mental disabilities, it cannot be considered as an anti-discriminatory legislation for the persons with disabilities.

- **The Legal Services Authorities Act, 1987:** The Legal Services Authorities Act, 1987 was enacted in the year 1987 to constitute legal services authorities to provide free and competent legal services to the society to ensure that opportunities of securing justice are not denied to any citizen by reason of economic and other disabilities. The act also made the provisions to organize Lok Adalats to secure that the operation of the legal system promotes justice on a basis of equal opportunity. It needs to be mentioned here that after the passing of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 (PWD Act 1995 hereinafter), the legal services Authorities Act defines disability in accordance with it.
- **The Motor Vehicles Act 1988:** The Motor Vehicles Act of 1988 is an amended version of the Motor Vehicles Act 1939 which consolidates the laws relating to motor vehicles. The act includes disability as one of the grounds of

refusal or revocation of license. The act tries to prevent the disables from being danger to the public. The Act also imposes a penalty on a person who drives a motor vehicle suffering from any disease or disability and such driving shall be the source of danger to the public. The penalty is fine extending up to Rs 200 and for the second subsequent offence with fine which may extend up to Rs 500 (Section 186).

- **The Public Liability Insurance Act 1991:** The Public Liability Insurance Act 1991 was passed to provide immediate relief to persons affected by accident occurring while handling any hazardous substances and for matters connected with it. According to the act in case of death or injury to any person (other than workman) or damage to any property resulted from an accident, the owner is liable to provide compensation for it (Section 3).
- **The Rehabilitation Council of India Act 1992:** The Rehabilitation Council of India Act was passed in 1992 (Act of 1992 hereinafter) to introduce rehabilitation councils for the welfare of the disabled people in India. The Rehabilitation Council of India (RCI hereinafter) was set up as a registered society under the aegis of the Ministry of Social Justice and Empowerment in 1986. On September, 1992 the Act was enacted by the Parliament and thereafter RCI became a statutory body on 22nd June, 1993 and later on in 2000 the act was again amended by the parliament. Under the act, the RCI is authorized to regulate and monitor services given to the persons with disabilities, to standardize syllabi and to maintain a Central Rehabilitation Register of all qualified professionals and personnel working in the field of Rehabilitation and Special Education. The act further prescribes punitive action against unqualified persons delivering services to the persons with disabilities (Rehabcouncil.nic.in). The process of rehabilitation of the disabled begins with early identification, prevention, intervention, integration and finally the rehabilitation. The RCI is also vested with the responsibility of framing policies and programmes for the development of manpower in the field of rehabilitation of disabled persons. Unless certified by the Council, no rehabilitation professional (audiologist, clinical psychologist, speech therapists etc.) is permitted to practice in his/her

field (Debi, 2017: p. 127). The Act of 1992 consists of three chapters, thirty sections and one schedule. The Act focuses on the rehabilitation of the following classes of disabilities: -

- Visual Disability
- Hearing Disability
- Locomotor Disability
- Mental Disability

For the rehabilitation of the above-mentioned disabled categories, the Act of 1992 has provided the status of a body corporate, having perpetual succession and common seal. This Act further authorizes the council to acquire hold and dispose of property –both movable and immovable and can take legal action (Section 11 and 12). The Council has been also empowered to recognize courses of study and process of examination of the rehabilitation professionals. On the report submitted by the Inspector or the Visitor, the Council can go to the extent of derecognizing such courses and examinations. The Member-Secretary possesses the authority to register the names of the professionals who has obtained the degree for becoming the rehabilitation professional (Section 17 and 19). The Act of 1992 provides for introduction of informal education, provision of aids and appliances and creation of adequate teacher training facilities to prepare the teachers for the special integrated schools. The Ministry of Social Welfare has bestowed upon the basic responsibility for conducting programmes for the disabled, and it delivers comprehensive rehabilitation services to the rural population. The Act also aimed at regulating the manpower development programmes in the field of education of the children with special needs (Section 20). The Council has also possesses punitive powers as it can do away with the names of the professionals from the register in case of professional misconduct. However, the aggrieved part can then appeal to the Central Government whose decision is final and binding.

- **The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995:** The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 (PWD Act hereinafter) is the first anti-discrimination legislation in the field of disability. The enactment of PWD Act is remarkable because for the first time in India since 1995, social and economic rights of persons with disability have been addressed by any statute (Kothari, 2012: p.xxi). Therefore, Sandra Fredman has referred PWD Act as an equality law in Indian legal history (Fredman, 2001: p.145). As mentioned earlier, in 1990s disability was become an emerging issue with the passing of various anti-discrimination legislations in different countries of the world where basic emphasis was upon positive action to remedy the disadvantage experienced by disabled persons. In India with the enactment of PWD Act emphasis on positive action by the state is congruent with three important and related development as Nick O'Brien outlines--- **first**, there is the philosophical and political prioritization in disability legislation of a new model of equality that puts at a premium the positive concepts of redistribution and participation at the expense of the more formal concept of non-discrimination. Thus, in order to enable them to gain access to work and other opportunities, differential treatment of disabled persons is required in many respects. **Second**, to promote equality there is the increasing prevalence of positive duties on the part of public sector. This is seen in the PWD Act as well, as it imposes several positive obligations on the state government and authorities to ensure a barrier free environment and where emphasis is given on prevention rather than cure. **Third**, there is the broad interpretation of constitutional principles that through the emerging case law on disability-related issues, constitutes a third wave of human rights jurisprudence 'that prioritizes notion of dignity, community, and participation at the expense of narrower conceptions of individual civil liberty' (O'Brien, 2004).

Definition of Persons with Disability under the PWD Act:

The PWD Act uses the broad category of people with disabilities and under a rubric puts the areas of functional limitation without really questioning the boundary lines (Ghai, 2003). Section 2(i) of PWD Act has specifically mentioned seven categories of disability while defining 'disability'-----

- i. Blindness
- ii. Low vision
- iii. Leprosy-cured
- iv. Hearing impairment
- v. Locomotor disability
- vi. Mental retardation
- vii. Mental illness

In addition, Section 2 (t) states that 'person with disability' means a person suffering from not less than 40 percent of any disability as certified by a medical authority.

It needs to be mentioned here that the definition of disability provided by PWD Act 1995 is a narrow concept as it has fixed forty percent as the criteria for determining disability which is entirely based on clinical assessment. Furthermore, the categorization of different forms of disability under the act is also limited in nature. The act only includes two categories under visual impairment viz. blindness and low vision. Other forms of visual impairments like colour blindness, night blindness or xerophthalmia are not incorporated in the act. Similarly, due to the social stigma associated with leprosy, the leprosy cured persons are not in a position to assert their rights and inclusion of leprosy cured as a category of disability remains on paper only.

Hearing impairment includes persons who are deaf and who are hard of hearing. In case of locomotor disability, the act only mentions about orthopedic disability, that is, impairment in the limbs. Other forms of disabilities like inability resulting from difficulty in the nervous system or muscular system are not incorporated in the act. There are, of course, wide ranging categories of disabilities such as muscular dystrophy, cystic fibrosis, multiple sclerosis, epilepsy, heart disease, persons suffering from HIV/AIDS etc. These people, specially, those suffering from HIV/AIDS have not received any statutory protection except from the constitution of India and the judiciary.

Objectives: The PWD Act has following objectives:

- a. To spell out the responsibility of the state towards the prevention of disabilities, protection of rights, provision for medical care, education, training, employment and rehabilitation of the persons with disabilities.
- b. To create a barrier free environment for the persons with disabilities.
- c. To remove any discrimination against persons with disabilities in sharing of development benefits vis-à-vis non-disabled persons.
- d. To counteract any situation of the abuse and the expectations of persons with disabilities.
- e. To lay down strategy for comprehensive development programmes and services and equalization of opportunities for persons with disabilities.
- f. To make special provision for the integration of persons with disabilities into social mainstream.
- g. Reservation in the identified posts, research and manpower development, establishment of homes for persons with severe disabilities.

The Act places responsibility on the society to make adjustments for disabled people so that they overcome various practical, psychological and social hurdles created

by their disability. The Act places disabled people at par with other citizens of India in respect of education, vocational training and employment. It seeks to establish a coherent and comprehensive framework for the promotion to just and fair policies and their effective implementation. It creates formal procedures, which hasten the process of full and total integration of the disabled in the society. It also aims at facilitating efficient enforcement of policies and permits strong measures against the law breakers (Pasayat, 2010: p.15). As regard education, the PWD Act mandates that all children with disability shall have the right to have access to free education up to the age of 18 years. Therefore, the act has vested a huge number of responsibilities to the state governments like making available of the basic amenities such as Braille books, appliances for vocational training etc. The act also talks about inclusive education means integration of students with disabilities in normal schools. Besides, the PWD Act imposes an obligation upon the Central and the State Governments to identify and reserve posts for the persons with disabilities. As per the act, three percent reservation should be maintained in case of public employment which is equally distributed among blind or low vision, hearing impaired and locomotor disabled. The act further states that if a person acquires disability during the course of employment cannot be deprived of his /her job. The act has also specifically mentioned the role of transport sector, within their economic capacity for the welfare of the disabled persons by initiating some special measures. For example, renovation of the rail compartments, buses, vessels and aircrafts can make the facilities accessible for the persons with locomotor disability. Moreover, for research and development of disability sector, the Act imposes responsibility to the local governments.

- **The National Trust Act 1999:** The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999 (NTA 1999 herein after) was enacted in the year 1999 with the aim to constitute a body at the national level for the welfare of persons with autism, cerebral palsy, mental retardation and multiple Disabilities. Section 10 of the act specified the objectives as follows:

- i. To enable persons with autism, cerebral palsy, mental retardation and multiple disabilities to live as independently and as fully as possible within their closed environment.
- ii. To extend support to registered organizations to provide need based services during period of crisis in the family of persons with disability
- iii. To deal with the problems of persons with disability who do not have family support
- iv. To promote measures for the care and protection of persons with disabilities after the death of their parents and guardians. The act also made certain provisions for the appointment of guardians and trustees for such disabled persons.
- v. To facilitate the realization of equal opportunities, protection of rights and full participation of persons with disabilities.

Again, Section 12 of the National Trust Act 1999 mentioned the procedure of registration through which any association or voluntary organization can become part of the National Trust and do welfare for the disability community. It is worthwhile to mention here that for the first time, under this act, disability of a person is being considered as the basis for appointing a legal guardian. Section 14 of the Act conferred the power of appointing or removing the legal guardians on the basis of the disability status of a person to Local Level Committees. The legal guardian will take care of the disabled person and his/her property.

- **Rights of the Persons with Disabilities Act 2016:** As discussed in the previous chapter the United Nations Convention on the Rights of the Persons with Disability 2006 (herein after UNCRPD) has brought a paradigm shift in disability rights. India was also a signatory of the convention and rectified the same on 1st October 2007. However, the existing legislation i.e., PWD Act 1995 at times failed to accommodate the broader horizon of disability as reflected in the UNCRPD. For example, the PWD Act incorporates an extremely narrow

definition of disability. It defines persons with disability as anyone having forty percent of disability or more in seven specific categories. On the other hand, article 1 of the UNCRPD defines, persons with disability include those who have long term physical, mental, intellectual and sensory impairments which in interactions with various barriers may hinder their full and effective participation in society on an equal basis with others. This is a very broad and inclusive definition so that all persons with any kind of long-term disability are covered by the protection of law. Another important idea as reflected in UNCRPD is the concept of reasonable accommodation. Article 2(5) of the convention defines reasonable accommodation as a necessary and appropriate modifications and adjustments that do not impose a disproportionate or undue burden where needed in a particular case. Under the PWD Act there is no specific reference made to the term reasonable accommodation. In a sense the PWD Act is a traditional non-discrimination law that emphasized the redistributive social policy giving rise to positive measures on the part of the state but without the backing of human rights. Hence, in the PWD Act a conceptual linkage between reasonable accommodation and non-discrimination is missing. Therefore, in the current scenario it was the need of the hour to enact a more forward looking equality legislation for protection of persons with disabilities in India. Accordingly, the new law called Rights of the Persons with Disabilities Act 2016 was passed on 27th December, 2016 by the parliament in the 67th year of the republic of India.

The act is mainly based on the principles for empowerment of persons with disability as reflected in the UNCRPD as given below:

- i. Respect for inherent dignity, individual autonomy including freedom to make one's own choice and independence of persons.
- ii. Non-discrimination
- iii. Full and effective participation and inclusion in society

- iv. Respect for difference and acceptance of persons with disability as part of human diversity and human being.
- v. Equality of opportunity
- vi. Accessibility
- vii. Equality between men and women
- viii. Respect for the evolving capacities of children with disability
- ix. Respect for the rights of children with disability to preserve their identity.

The Act includes twenty-one types of disability under five broader categories.

- i. Physical Disability
 - a. Locomotor disability (leprosy cured, cerebral palsy, dwarfism, muscular dystrophy, acid attack victim)
 - b. Visual impairment (blindness, low vision)
 - c. Hearing impairment (Deaf-means person having 70DB hearing loss in speech frequencies in both ears, hard of hearing)
 - d. Speech and language disability
- ii. Intellectual disability
 - a. Specific learning disability
 - b. Autism spectrum disorder
- iii. Mental illness
- iv. Disability due to:
 - a. Chronic neurological condition such as multiple sclerosis, Parkinsons' disease

- b. Blood disorder such as haemophilia, thalassemia, sickle cell disease
- v. Multiple disabilities (more than one of the above specified disabilities)

2.5 Census and Disability in India:

As mentioned earlier, with the inception of modern census in India in 1872, data collection related to disability/infirmity was introduced in India. However, this practice was discontinued in census of 1941, 1951, 1961 and 1971. After independence, it was again introduced only in the year 1981. It needs to be mentioned here that the United Nation Organization has proclaimed the year 1981 as the International year for the Disabled Persons and most of the countries of the world included disability in their censuses. Hence, after a gap of 50 years, or four decennial censuses, the issue of disability was again campaigned for 1981 census. The 1981 census included only three categories of disability viz., ‘Totally Blind’, ‘Totally Dumb’ and ‘Totally crippled’. The categories like hearing impairment, low vision, mentally retarded etc were not incorporated in the census data as the enumerators found it difficult to gather information. The people also did not want to disclose the information regarding disabled person in their respective families. However, the Ministry of Social Justice and Empowerment had assured that they would give training to undertake certain sensitization programme for the enumerators. This census revealed that at the national level 0.2% (1.1million) of the population was disabled. Among them 43% were blind 32% were Crippled and 25% were dumb (censusindia.gov.in). The issue of disability again dropped in 1991 census and as a result of long struggle by the disabled people it was reintroduced in 2001 census after the passing of PWD Act 1995. The Disability movements taking place in different parts of the world made the disabled people aware about the fact that until and unless data regarding disability are not incorporated in the census, the rights and demands of the disabled people cannot be fulfilled. It is worthwhile to mention the fact that over a thousands of people gathered at Jantar Mantar on 7th March, 2001 to appeal the Government for the incorporation of disabled population in 2001 census. Again on 24th April, 2001 another demand was made by

different NGOs and disability activists in a protest movement all over the country to fix the enumeration and incorporation of different types of disability in the 2001 census of India. On 11th June Government of India has made the official announcement to include disability in 2001 census. The 2001 census of India included the following categories of disability in its report:

- i. Seeing
- ii. Speech
- iii. Hearing
- iv. Movement
- v. Mental illness

The table given below shows the number of total disabled population and their percentage in accordance with different types of disability.

Table 2.2: Distribution of Population in accordance with their Disabilities in 2001 Census:

Category/ Population	Total no of disabled persons	Percentag e of disabled population in total population	Distribution percentage in accordance with Disability				
			Seein g	Speec h	Hearin g	Movemen t	Mentall y Illness
Total	2109700 0	2.13	49	7	6	28	10
Rural	1638800 0	2.21	48	8	6	28	10
Urban	5518000	1.93	50	7	4	26	12
Male	1260600 0	2.37	46	8	5	31	11
Female	9301000	1.87	53	8	6	24	10

Source: Census Data Survey 2001.

In 2011 Census an effort had been made to collect data on disability in an extensive manner as the National Policy for Persons with Disabilities 2006 recognizes disabled people as valuable human resources and seeks to create an environment that provides equal opportunities, protection of their rights and full participation in the society. To facilitate this national objective, there is a need for collection, compilation and analysis of data on disability (Census,2011). Therefore, certain new approaches were adopted in collecting data on disability such as preparation of ‘Household Schedule’ where questions on disability were asked to all the persons in the household. Apart from taking interview of the all the family members of the household, the enumerators were also instructed to contact the disabled person. All types of households i.e., ‘Normal’, ‘Institutional’, ‘Houseless’ households were covered by 2011 census (Office of the Registrar General and Census Commissioner). The Census 2011 also highlighted the use of simple nomenclature of the types/ categories for the convenience of both the enumerators and respondents. While categorizing the different types of disability, the 2011 Census covered all the categories mentioned both in the PWD Act 1995 and National Trust Act 1999. Accordingly, data were collected from the following eight types of disability:

- i. In seeing
- ii. In hearing
- iii. In Speech
- iv. In movement
- v. In Mental Retardation
- vi. In mental illness
- vii. Any other
- viii. Multiple Disability

It needs to be mentioned here that in 2011 census three new categories of disability i.e., mental retardation, any other and multiple disability were added which were not found in 2001 census. A person who is lacking the understanding/comprehension as compared to his/her own age group, unable to communicate his/her needs and cannot perform his/her daily activities is considered as mentally retarded person according to 2011 census. 'Any other' and 'multiple disability' categories are two important addition of 2011 census. Persons belonging to 'Any other' category are those who do not fall any one of the categories listed above. Generally, a disability like 'Autism' is included in this category. As regard multiple disabilities, it refers to the combination of two or more specific types of disability. Besides, certain modifications were also made in the remaining categories of disability. For example, in 2001 census, one eyed persons were treated as disabled, but in 2011 Census such persons were not included in the list. In seeing category, 2011 census enumerators were asked to apply a simple test to determine the blurred vision of the respondent which was not there in 2001 census. Similarly, in hearing category persons using hearing aid were considered as disabled in 2011 census not in 2001 census. In speech category the definition was made more distinct in 2011 census, which defined "persons who speak in single words and are not able speak in sentences as disabled". In identifying the disabled persons in movement category 2011 census has specified some important points like person in paralysis and cannot walk but can crawl, those who have acute and permanent problems of joints/ muscles, difficulty in balancing and coordinating body movements, leprosy cured persons, persons having deformed body like hunch back etc. In 2001 census mental illness was covered under mental disability category. However, under mental illness category, new incorporations were made like persons taking medicines or other treatment for mental illness, exhibit repetitive (obsessive-compulsive) behaviour/ thoughts, have difficulty in social interactions and adoptability etc. in 2011. The table given below shows the rural-urban and male-female categories of disabilities in percentage.

Table2.3: Number and Percentage of Disabilities in accordance with male-female and rural-urban categories in 2011 census:

Residence	Disabled Persons		Males		Females	
	No	Percentage	No	Percentage	No	Percentage
Total	26,810,557	2.21	14,986,202	2.41	11,824,355	2.01
Rural	18,631,921	2.24	10,408,168	2.43	8,223,753	2.03
Urban	8178636	2.17	4578034	2.34	3600602	1.98

Source: Census Data Survey 2011

2.6: Education and Disability in India:

The Constitution of independent India clearly reflects certain provisions that give directions to the states to ensure requirements of basic education to all the children up to 14 years of age. The article 45 under the directive principles of state policies of the Indian constitution suggests that the state shall endeavour to provide early childhood care and education for all children until they complete the age of six years (Bakshi 2006, p.90). However, the education of the children with disabilities was not explicitly mentioned in it. It was the Kothari Commission's recommendations (1964-66) (Education and National Development, 1966), drew attention to the education of children with disabilities. Based on the Kothari Commission's recommendations the first National Policy on Education (NPE hereinafter) was announced in 1968, which called for a 'radical restructuring' and 'equalize educational opportunities.' The article (4) of NPE 1968 refers Equalization of Educational Opportunity in such manner: *Strenuous efforts should be made to equalize educational opportunity- educational facilities for the physically and mentally handicapped children should be expanded and attempt should be made to develop integrated programmes enabling the handicapped children to study in regular schools.* Again, in 1974 Integrated Education for Disabled Children (IEDC) scheme was introduced with the intention of initiating the system of integrated education. The term integrated education as mentioned in IEDC means, 'to form into a whole, to complete' by providing the least restricted environment to

children with disabilities so that they may grow and develop like rest of the population. IEDCS's aim was to cover up children with disabilities under the regular system of education in 27 states and 4 union territories (MHRD, 1992). However, it was reported in a book '*Physically Handicapped in India*' written by R. Mani that till 1979-80, the programme benefitted only 1881 children from 81 schools across the country (Mani, 1988). Again, in 1976 the 42nd constitutional amendment made education as a combined responsibility of both the governments-states and union. In May 1986, NPE was revisited with certain modifications and changes of earlier NPE 1968. The Article 4.9 of the policy document states that:

The objective of NPE should be to integrate the physically and mentally handicapped with the general community as equal partners, to prepare them for normal growth and to enable them to face life with courage and confidence. The following measures will be taken in this regard---

- a. Wherever it is feasible, the education of children with motor handicaps and other mild handicaps will be common with that of others*
- b. Special schools with hostels will be provided, as far as possible at district headquarters, for the severely handicapped children.*

It is evident from the article 4.9 of the NPE 1986 that the policy tries to emphasize both on integration and special school. However, till 1992 the NPE 1986 was not implemented. In 1992 the Programme of Action (POA hereinafter) was created to bring certain modifications for practical application of NPE 1986. It needs to be mentioned here that although the article 4.9 of NPE remained unchanged, the POA has tried to bring out certain basic issues for discussion. It suggested that the children with disability who can be integrated in regular schools must accommodate there and those who are not in a position to acquire skills such as daily living skills, etc, may be entitled to special set-ups. But, after acquiring the basic living skills the children with disabilities are to be shifted to the regular school. However, POA was not clear about the basic skills to be acquired by the children with disabilities. Besides, the POA also envisioned the provision for the set up of additional 400 special schools at the district headquarters. But, the concerned authorities were not in a position to establish even a single special school due to limited resources. Some resource centres were established

in the regular schools to be run after normal school hours, eliminating the possibility of inclusion for the children with disabilities (Verma, Christopher and Jha, 2007). In 1987, the Ministry of Human Resource Development along with National Council of Educational Research and Training and the United Nations Children Emergency Fund (UNICEF) initiated the Project for Integrated Education for the Disabled (PIED) which endeavors to reinforce the IEDC 1974 plan. The 'Composite Area Approach' of PIED, all the regular schools of a particular area got transformed into integrated schools. According to Azad (1996), approximately 13000 children with disabilities got accommodated in regular schools and more than 9000 teachers received training to work with them.

As mentioned earlier, Rehabilitation Council of India (RCI) became a statutory body in 1993 after passing of Rehabilitation Council of India Act 1992 and RCI was vested responsibilities like training of the personnel who will be engage in educating the people with disabilities, preparation of curriculum for persons with disabilities etc. A major shift in the protection of economic as well as social rights of the disables was witnessed with the passing of PWD Act 1995. The Act states to make provisions of education, employment and creation of barrier free environment and highlights the need for both special schools and integration. The article 26 of the Act specifically mentions about it:

The appropriate government and local authorities shall-----

- a. promote setting of special schools in Government and Private sector for those in need of special education in such a manner that children with disabilities living in any part of the country have access to such schools.*
- b. Endeavour to promote the integration of students with disabilities in the normal schools.*

The act further refers to set up teachers' training institutions to develop trained manpower for both special schools and integrated schools for children with disabilities (Article 29 of PWD Act 1995). Again in 1995, projects like "District Primary Education Program" (DPEP) (with support from World Bank) was also initiated with the objective to provide Education for All by the year 2000, more specifically providing inclusion of children with mild and moderate disabilities. According the World Bank

(2007), by the year 2006, in 23 districts of three states viz, Rajasthan, Orissa and West Bengal 6, 00,000 children with disabilities were enrolled under DPEP. Kumar, Priyam and Saxena (2001) concede that there was a fall in growth at the enrolment in the primary education, although DPEP was introduced in 240 districts across 16 states. In 2002, government launched a new scheme i.e. Sarva Shiksha Abhiyan (SSA) for the universalization of elementary education. In this effort, the three important aspects are access, enrolment and retention of all Children with Special Needs in 6-14 years of age. Further, the 86th constitutional amendment in 2002 has strengthened this commitment by declaring free and compulsory education as a fundamental right for all the children up to the age of 14 years by including article 21.A in Part III of Indian constitution. In the SSA framework, the concept of inclusive schooling education was introduced which aims at achieving social justice and equity in our society. Inclusive schooling education is often thought as the inclusion of students with disabilities, regardless of ability, into the same schools and classrooms with peers who are not considered to have disabilities. Inclusive schooling, in fact tries to broaden the horizon of disability from physical limitation to socio-cultural constraints. In addition, National Institute of Open Schooling established in November 1989 as an autonomous organization in pursuance of National Policy on Education is also promoting inclusive education by registering children with disabilities through accredited institutions, accredited vocational institutions, special accredited institutions for the education of the disadvantaged and open basic education. Through National Institute of Open Schooling Learning materials, audio-visuals cassettes or working kits can reach the doorsteps of disabled learners. In 2000, the National Institute of Open Schooling also established a Cell for the Education of the Disabled to develop user friendly study materials for children with learning disabilities and also for visually impaired persons. Again, in 2009 Right of Children to Free and Compulsory Education (RTE) Act mandates free and compulsory elementary education to all children aged 6 to 14 years. In article 3(2) of the Act, it is mentioned that the right to education of a child with disability is to be governed by the provisions of PWD Act 1995.

While analyzing the policy framework and legal provisions for education for persons with disabilities, it is pertinent to mention the distinctions among the conceptual categories like special education, integrated education and inclusive education. In the

initial stage, the whole discourse of disability education was marked by a segregationist approach to education of the children with disabilities that required a kind of special arrangement for those children who are labeled or certified as disabled or who are ineducable in the so-called normal educational institutions. With the emergence of social model of disability particularly in the later part of twentieth century integrated education assumed significance in the domain of disability education where both disabled and non-disabled children can get access to education. The emphasis is given on barrier free environment and accessibility in terms of physical, communicative, social, attitudinal, educational and institutional. On the other hand, the idea of inclusive education is both conceptually and philosophically broader than that of the integrated education. Inclusion is not a static idea like integration, but it is dynamic process that implies changes in institutional ethos to create a community that accepts and values differences. For inclusion to work curriculum content rather than merely curriculum delivery much change where the child's right to belong to a mainstream institution does not remain a matter of legal rights, but become their moral and political rights. The institutions should re-structure the curriculum to include disability issues and positive portrayal of persons with disability in a non-patronize and non-stereotypical ways. In case of India, up to the PWD Act of 1995 both special and integrated education were given parallel emphasis as PWD Act was predominantly influenced by medical model of disability that gives much importance on prevention or early detection of disabilities, special education was an integral part of the whole endeavour. Article 49 of Chapter IX of PWD Act made certain provisions for financially assisting research on special education undertaken by universities, institutions and non-governmental organizations. It also emphasized on imparting education through open school and open universities. At the same time, as stated earlier the PWD Act in its article 26 mentioned that the appropriate government and local authorities shall endeavour to promote the integration of student with disabilities in to normal schools. However, this act was quite silent regarding the inclusive education for the persons with disabilities.

The RTE Act 2009 is the most comprehensive act that ensures at least twenty five percent enrolment for weaker and disadvantaged sections applies to un-aided and special category schools. However, regarding inclusive education for the children with disabilities, the act was almost silent. As regard the right to education of a disabled

child, the Act only refers to the chapter V of the PWD Act 1995. The idea of inclusive education has well addressed only in the recent past with the enactment of Rights of the Persons with Disabilities Act (RPWD) 2016. The Act established a logical linkage between inclusive education and reasonable accommodation according to the requirements of the individuals. Article 16 of Chapter III mentioned that the appropriate government and local authorities shall endeavour that *all educational institutions funded or recognized by them provide inclusive education to children with disabilities and towards that end shall---*

- i. *Admit them without discrimination and provide education and opportunities for sports and re-creation activities equally with others*
- ii. *Make building, campus and various facilities accessible*
- iii. *Provide reasonable accommodation according to the individual's requirements.*
- iv. *Provide necessary support individualized or otherwise in environments that maximize academic and social development consisted with the goal of full inclusion.*
- v. *Ensure that the education to persons who are blind or deaf or both is imparted in the most appropriate languages and modes and means of communications.*
- vi. *Detect specific learning disabilities in children at the earliest and take suitable pedagogical and other measures to overcome them.*
- vii. *Monitor participation, progress in terms of attainment levels and completion of education in respect of every student with disability*
- viii. *Provide transportation facilities with the children with disabilities and also the attendant of the children with disabilities having high support needs.*

Thus, the Act has well defined the idea of inclusive education in respect of different types of disabilities. It needs to be mentioned that in 2019 the Government of India made certain amendments to the RTE 2009. However, these amendments also did little to encourage inclusive education for persons with disabilities.

2.7 Disability and the Issue of Rehabilitation in India:

Rehabilitation is an important aspect of disability. It is an integral part of the medical model of disability that has been discussed in the previous chapter. Under rehabilitation approach efforts are made to cure impairment and to normalize the functional limitations of persons with disabilities. When medical science fails to offer a cure then rehabilitation or necessary measures are extended in the educational and occupational areas of life of the impaired person. The process of rehabilitation of the disabled persons is a long process which begins with early identification, prevention, intervention, integration and finally the rehabilitation. The RPWD Act 2016 defines as rehabilitation in its chapter 1 (*za*) as a process aimed at enabling persons with disability to attain and maintain optimal, physical, sensory, intellectual, psychological, environmental or social function levels. Rehabilitation council of India Act (RCI Act hereinafter) was the one of the significant legal steps that India has adopted for the rehabilitation of disabled persons in India. However, establishment of RCI in 1986 as a registered body which was converted into a statutory body after the enactment of RCI Act 1993 was also an important step for rehabilitative approach of the government. It is worthwhile to mention here that the planned economic development model was the most dominant model of development in India in the aftermath of independence. Hence, the five-year planning process of the Government of India also initiated certain rehabilitation programmes for the persons with disabilities. During the first five-year plan (1951-56) National Advisory Council for Education of the handicapped was set up and in 1955-1956 and a scheme of scholarship for the deaf students, receiving technical training in the ordinary technical institution was initiated. In the second five-year plan, special employment exchanges for the handicapped were established and Rs. 24 lakh was earmarked for various welfare measures for the blind. Besides, model schools for the deaf and audio logical centre and technical training centre for the adult deaf was established during the period of second five-year plan. In the third plan, proposal was taken for the establishment of training centre for adult deaf. The fourth (1969-1974) and fifth plan (1974-1979) encouraged the state governments to introduce integrated education for the disabled children in the ordinary school. In the sixth five-year plan emphasis was given to create opportunities for integrated education, vocational training

and economic rehabilitation. For this purpose, various skill training programmes were launched in collaboration with the local industry to promote employability. Although, the Seventh five-year plan (1985-1990) was not specific about disability rehabilitation schemes, it campaigned for health for all including the persons with disabilities. In the Eight plan (1992-1997) steps had been undertaken to provide technical training in polytechnics to 12 million physically disabled persons and accordingly fifty selected polytechnics were upgraded to integrate the disabled students specifically for orthopedically disabled and partially deaf and dumb. The main objective of Ninth Plan was growth with social justice and equity. Therefore, the Ninth five-year plan emphasized on integrated education for the disabled and role of open and distance learning system in imparting education to the disabled was also realized during ninth plan period. Besides, during Ninth plan the Department of Youth Affairs and Sports instructed to formulate special scheme for the promotion of sports and games among the four categories of disabled persons viz., blind and visually handicapped, Deaf and Dumb, Mentally Retarded and orthopedically handicapped. The Tenth Five-year plan (2002-2007) highlighted for the effective implementation of PWD Act 1995 to ensure social justice to the disabled people with equitable terms. The plan also proposed to strengthen and consolidate the outreach and extension programmes through National programme for Rehabilitation of Persons with Disabilities (NPRPD). It needs to be mentioned here that the NPRPD was launched in the year 2000-2001 with the objective of providing minimum level of services at each level in the states with a three-tier structure right from the village level through the Mandal, District and State. Initially, in the state of Andhra Pradesh, five districts have been chosen for implementing the NRPRD. In the eleventh five years plan, Department of Disability Affairs was established in the Ministry of Social Justice and Empowerment to act as the nodal department for overall policy, planning and coordination of programmes for persons with disabilities. Accordingly, District Disability Rehabilitation Centres (DDRCs) at the district level and Composite Regional Centres (CRCs) at the state level were established. District Disability Rehabilitation Centres are for taking care of all the disabilities which is mostly community-based organization (CBO) involving the local resources as partner and the Composite Regional Centres were set up to conduct training programmes for the professionals working in the field of rehabilitation along

with certain extension services for the disabled people. At present, there are Composite Regional Centres functioning at Sundernagar, Srinagar, Lucknow, Guwahati, Patna and Bhopal. Besides, scheme for financial assistance for persons with disabilities to purchase artificial limbs was launched during this plan period. The Eleventh five-year plan tried to extend its horizon to the private sector by launching the scheme of incentive to employers in the private sector for providing employment to persons with disabilities. The initiatives during Twelve Five Year Plan (2012-2017) include service delivery and stepping up the level of awareness, generation of public awareness about disability rights, establishment of Centre for Disability Sports (CDS), recognition, empowerment and protection of persons with disabilities etc.

It is noteworthy to mention that prior to the eleventh plan in 1985 the Government of India also introduced a holistic scheme to establish the linkages among peoples' participation, medical institutions and rehabilitation of disabled persons at micro level. Accordingly, efforts were made to establish District Rehabilitation Centres (DRC hereinafter), Primary Level Rehabilitation Unit (PRU hereinafter) and recruitment of a few rehabilitation workers at local level like Primary Rehabilitation Assistant (PRA hereinafter) and Village Rehabilitation worker (VRW hereinafter). The main functions of DRCs were to coordinate the activities of all government agencies in the district, to provide technical and administrative support to PRUs, to initiate action to set up special schools, vocational training programme etc. The PRUs were to be attached to the Primary Health Centres at the block level. They provide administrative and technical support to the PRA and VRW. Besides, counseling for the disabled, organizing mass immunization programmes in coordination with Primary Health Centres, assisting disabled children in receiving education etc were also done by the PRUs. The PRA was assigned the responsibility to supervise the status of rehabilitation process in 20-30 villages. The PRAs were locally recruited and they tried to prepare rehabilitation plans with the help of professionals and refer the disabled persons of their locality to appropriate referral centres. They were also assigned the duty to supervise, train and guide the VRWs who were there at the grass root level of this rehabilitation scheme. VRWs are also locally recruited in the villages consisting of about 1000 population. VRWs mainly tried to identify the disabled individuals in the village and create awareness in the village about the availability of rehabilitation services. Apart

from these under the supervision of Ministry of Labour and Employment, Government of India, a number of Vocational Rehabilitation Centres (VRCs) were set up in different parts of the country. At present twenty-one VRCs are in functional mode. Besides, in the field of employment and education the RPWD Act 2016 adopted a number of provisions for rehabilitation of persons with disabilities. For instance, under article 32(i) mentioned that all Government institutions of higher education and other educational institutions receiving aids from the government shall reserve not less than five percent seats for persons with benchmarked disabilityⁱ. Again, according to article 34 (i), every appropriate government shall appoint in every government establishment not less than four percent seats of the total number of vacancies. Prior to this the PWD Act 1995 also made the provision of three percent reservation of posts in government establishments for persons with disabilities under its article 33.

After the enactment the first disability legislation in 1995, the government of India adopted a number of policies and schemes for the implementation of the act. For instance, in 1999 ‘Scheme to Promote Voluntary Action for Persons with Disabilities’ was initiated by the central government which was revised and renamed as Deendayal Disabled Rehabilitation Scheme (DDRS) in 2003. The scheme has two broad objectives:

- To create an enabling environment to ensure equal opportunities, equity, social justice and empowerment of persons with disabilities.
- To encourage voluntary action for ensuring effective implementation of the PWD Act of 1995.

The DDRS provides financial assistance to voluntary organizations to make the services available for rehabilitation of persons with disabilities. The services under DDRS include early intervention, development of daily living skills, education, skill-development oriented towards employability, training and awareness generation. Under DDRS scheme, the voluntary organization can get grant-in-aid from Ministry of Social Justice and Empowerment, Government of India for the projects like establishment of vocational training centres, set up of special schools for persons with disabilities,

project for cerebral palsied children and early intervention and training, rehabilitation for Leprosy Cured Persons, steps for Community Based Rehabilitation, construction of disability friendly buildings, organizing seminar/workshop/rural camp, half way home for psycho-social rehabilitation of treated and controlled mentally ill persons etc. Again, in 2006 National Policy for Persons with Disabilities launched by the central government which recognizes that the persons with disabilities are valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society. The rehabilitation measures under the policy can be classified in to three distinct groups:

- Physical rehabilitation, which includes early detection and intervention, counseling and medical interventions and provision of aids and appliances. Training and development of rehabilitation professionals are also included in this group.
- Educational rehabilitation including vocational education.
- Economic rehabilitation for a dignified life in society.

Meanwhile, central government launched another Scheme for implementation of Persons with Disabilities Act (SIPDA), which provides grant-in-aid to State Governments, organizations of Central/ State Governments, including autonomous bodies and universities, for creating barrier free access to their building; making websites accessible, and for early detection and diagnosis of hearing impaired (Kacker, 2013: p.6). More recently, on 3rd December 2015 Department of Empowerment of Persons with Disabilities has launched Accessible India Campaign, a scheme to achieve universal accessibility for Persons with disabilities. The scheme has three important components:

- a. **Built Environment Accessibility** includes the measures to eliminate obstacles and barriers to indoor and outdoor facilities including schools, medical facilities and workplaces.

- b. **Transportation System Accessibility** includes making all types of transportation viz, air, train, bus, taxi accessible for disabled people.
- c. **Information and Communication Ecosystem Accessibility** refers to all information which are essential for day-to-day affairs of a person with disability as an individual.

2.8 Institutional Arrangements for Disabled Persons in India:

Institutions are the vehicles through which any kind of policy arrangement and legislations are implemented to achieve the desired goal. The study of institutions is essential to understand the differences between the ideals and the practices of a particular social phenomenon. Hence, to understand the practices of disability affairs, it is essential to know the institutional arrangements made for the persons with disabilities and their functioning at various levels to attain the objectives of different policies and legislations of the Government of India. It needs to be mentioned here that the Ministry of Social Justice and Empowerment is the nodal ministry for implementing the policies and programmes for the persons with disabilities. In May 2012, under the Ministry of Social Justice & Empowerment the Department of Disability Affairs was created to give greater emphasis on their policy issues and implementation. Besides, Ministry of Women and Child Development, Ministry of Human Resource Development, Ministry of Labour and Employment, Ministry of Health and Family Welfare, Ministry of Urban Development, Ministry of Housing and Urban Poverty Alleviation, Ministry of Rural Development, Department of Higher Education, Department of Personnel & Training, Department of Science and Technology and Department of Scientific and Industrial Research also have their own policies pertinent to disability. The office of the Chief Commissioner for Persons with Disabilities, National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities and the Rehabilitation Council of India are the three statutory bodies related to the issue of disability. According to the article 42 of the PWD Act 1995 the Chief Commissioner for Persons with Disabilities has been set up to protect the rights of the persons with disabilities. It is a quasi-judicial statutory body and the PWD Act 1995 empowers the

commissioner to take up the cases based on complaint regarding the violation of any provision of the act. The commissioner can also issue suo moto notice from his end. Similarly, the RPWD Act 2016 in its chapter XII, article 74 to 83 has made the provision for Chief Commissioner at the national level and state commissioners at state level for the protection of the rights of the persons with disabilities. As mentioned above, National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities was formed under NTA 1999. The basic objectives of the trust are to ensure persons with disabilities to lead independent life with dignity, support and strengthen NGOs and other service providers, appoint legal guardians to take care the needs of persons with disabilities. The trust conducts certain training and awareness programmes related to the issues like capacity building, shelter and empowerment of the persons with disabilities. Again, the main functions of Rehabilitation Council of India are to regulate and monitor the training of rehabilitation professionals and personnel and promote research in rehabilitation and special education. In addition to these, under Ministry of Social Justice and Empowerment seven national institutes are engaged in different aspects of disability like human resource development, rehabilitation services and research and development. These national institutes including their regional centres and composite regional centres run eighty courses of one year and more duration. These seven institutes are:

1. **National Institute for the Visually Handicapped (NIVH), Dehradun:** The National Centre for Blind, which was established by the central government in the year 1967 upgraded as NIVH in the year 1979. NIVH mainly sponsors the training of trainees and teachers, employment officers, psychologists, vocational counselors and other personnel necessary for evaluation, training and rehabilitation of visually handicapped.
2. **National Institute for the Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai:** NIEPMD was established in the year 2005 to serve as a national resource centre for persons with multiple disabilities such as those with two or more disabilities in a person.
3. **Swami Vivekanand National Institute for the Rehabilitation, Training and Research (SVNIRTAR), Cuttack:** SVNIRTAR was established in 1975 as an

autonomous body to provide total medical rehabilitation for the persons with locomotor disability. The institute also conducts three graduates as well as post-graduate degree courses in physiotherapy, occupational therapy, prosthetics and orthotics.

4. **Ali Yavar Jung National Institute for the Hearing Handicapped (AYJNIHH), Mumbai:** AYJNIHH came into being as an autonomous institute under Ministry of Social Justice and Empowerment in the year 1986. The objectives of the institute are to provide rehabilitation to the hearing impaired. It also offers not only some undergraduate and post graduate courses for the hearing-impaired people, but also promotes research in their respective fields.
5. **National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID), Secunderbad:** NIEPID {formerly National Institute for the Mentally Handicapped (NIMH)} was established in 1984 to provide certain basic services so that the persons with intellectual disabilities can lead a quality life. It has three regional centres located at New Delhi, Kolkata and Mumbai. The institute has developed various training courses and programmes on the issues like early intervention, rehabilitation psychology, disability rehabilitation and special education. NIEPID has also certain extension and outreach programme to make people about the problems of the persons with intellectual disabilities.
6. **National Institute for Orthopedically Handicapped (NIOH), Kolkata:** NIOH was established in the year 1978 under Ministry of Social Justice and Empowerment. The services provided by the institute are specialized research services, standardization of aids and appliances, documentation and dissemination, consultancy services for the orthopedically handicapped.
7. **Pt. Deendayal Upadhaya National Institute for Persons with Physical Disabilities (PDUNIPPD), New Delhi:** PDUNIPPD was formerly known as the Institute for Physically Handicapped. The Institute for physically handicapped came into being when erstwhile Jawaharlal Nehru Institute of Physical Medicine and Rehabilitation and other allied institution run by the council of Aid of

crippled &handicapped were taken over by the Government of India on 22nd May 1975 and converted into an autonomous body in the year 1976. It was renamed after Pt Deendayal Upadhaya in 2002. The services offer by the institute are clinical services, occupational therapy, OPD physical therapy, speech therapy, artificial limbs, aid and assistive device fitting according to needs, special education.

2.9 Conclusion:

The present chapter provides a brief overview of the trajectory of the idea of disability from pre-historic period to the contemporary time in India. Effort has been made to understand how the concept of disability evolves through ages as a social category in the complex cultural milieu of Indian society and tries to explore the portrayal of disability in the religious and mythological narratives. When colonialism entered in Indian society, the issue of disability gradually changed its character from a social imaginary to an empirical reality with the introduction of modern census. After independence, some initiatives have been undertaken on the part of the state to provide certain social security measures to the disabled people. However, in the initial years, the issue of disability was closely connected to warfare. The first line of thinking towards providing social security to the disabled persons in India started only after 1971 Indo-Pak war particularly to the war victim soldiers. Gradually, it entered into the broader domain of welfare framework of the state. Once the first full-fledged disability legislation came into being in 1995, the whole issue of disability became a right based issue and it was being further reasserted more prominently with the enactment of RPWD Act 2016. While PWD Act 1995 was more influenced by medical model of disability, the RPWD Act 2016 is primarily marked by the social model of disability. The institutions are another important aspect of disability through which various policies pertinent to disability like education, rehabilitation, medication is transformed into practice. A number of institutions are set up in India to look after the disability affairs in the recent past. The accommodation of disabled persons in the mainstream society and the success of policy implementation mainly depends upon the performance of the institutions. Hence, study of the disability institutions is essential to understand

the level of execution of disability policies and legislations at different level. The proceeding chapters of the present study will mainly focus on the functions and the performance of the institutions of disability with a micro level study in the state of Assam.

ⁱ RPWD Act 2016 defines Benchmark disability as a person with not less than forty percent of a specified disability where specified disability has not been defined in miserable terms and includes a person with disability where specified has been defined in miserable terms as certified by the certifying authority.

CHAPTER III

A BRIEF PROFILE OF INSTITUTIONS RELATED TO DISABILITY IN ASSAM

3.1 Introduction:

Institutions are those apparatus of State through which it governs a particular social phenomenon. Different institutional arrangements are made for conducting various types of governance by the State. Governance is the process which involves all the elements of a society which exert power and authority to persuade and enact policies and decisions regarding public life, economic and social development of a given society. Governance is not only concerned with structure and processes for decision making, accountability, control of a particular institution but also related to objectives and performances of it. In fact, it focuses on the dynamic interplay between structures and processes, institutions and actors, rules and their application (Benz, 2004, p.18; see also Mayntz, 2005, pp.11-20). However, Micheal Foucault has provided an alternative understanding of governing a particular phenomenon by the State (Foucault and Senellart (eds), 2008, p. 186). He mentioned about the totality of institutions and practices and multiple levels of power structure ranging from administration to education by which people are governed. Foucault used the concept of governmentality to explore the complex technique of governance by the State at different level. Governmentality refers to the particular shape of power where soft techniques of governance are used by different institutions in a given society. To explore these soft techniques of governance, Foucault also uses the term 'bio-power', refers to the conquest of bodies and the control of the population (Foucault and Senellart (eds), 2008, Pp. 185-213). Hence, the problems that affect birth rates, life spans, public health, migration, settlement, disability etc. have become political problems and institutions such as schools, hospitals, barracks, shelter houses, factories etc. that have begun to

influence peoples' life and a new form of knowledge such as Sociology emerge as indispensable conditions for practices of governance (Foucault, 1977, p.166f). Accordingly, modern State has become not only the creator but also the diffuser of these techniques. In a way, State itself is an institution or a set of institutions entrusted with making and enforcing the rules of a society. Through various ministries, departments, institutes and organizations State implements its policies at different level. It needs to be mentioned here that in a democratic regime to promote the general welfare of the people State creates and re-creates institutions and henceforth the principles of State legitimacy which is constructed through policies that aim at providing services to the people. (A Roy, 2016, p.161).

As stated in the previous chapter, to address the issue of disability, Indian State has also made certain institutional arrangements in different point of time at various levels starting from the grass root level to the national level. Assam, one of the North Eastern states of India is the area for the empirical investigation of the present study. According to 2011 census, the total number of populations in Assam is 31,169,271, out of which the disability population is 4,80,065. The percentage of male disabled population in Assam is 53.5 percent, whereas 46.4 percent are female. Further, 86.5 percent of the disabled are from rural areas and only 13.5 percent from urban areas. As regards the types of disability, it is reflected in the census data that the higher proportion (21.2%) is due to hearing impairment, which is followed by other causes (18.2%), vision impairment (16.8%), movement disability (15.8%), multiple disability (10.3%), speech disability (8.3%), mental retardation (5.5%) and mental illness (3.9%). In Assam 51.7% disabled persons are literate and 48.3 percent are illiterate.

3.2 State Institutions Pertinent to Disability in Assam:

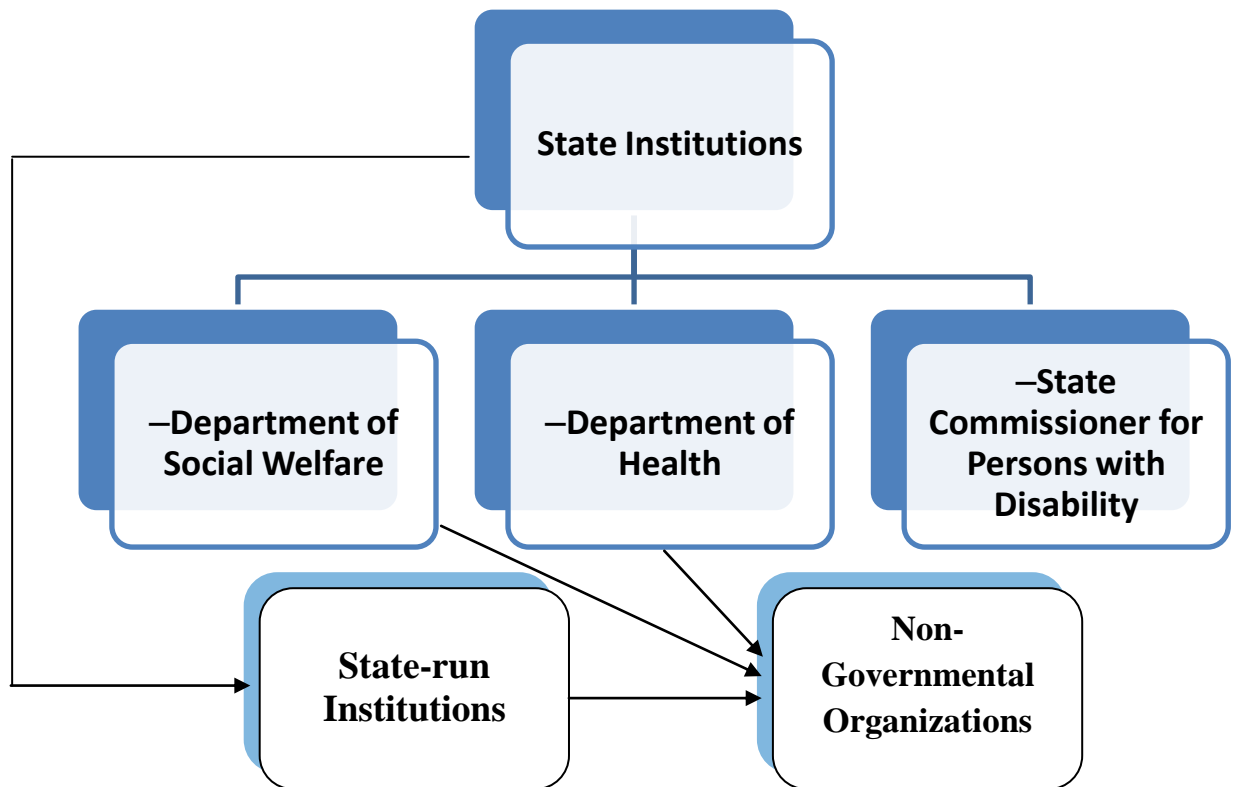
Assam witnessed the establishment of a number of institutions related to disability particularly after the enactment of PWD Act 1995. However, prior to that a number of non-governmental organizations (NGOs hereinafter), philanthropic institutions, special schools like blind schools, schools for deaf and dumb etc. were established in different parts of the state with certain specific objectives. Before giving the profile of the disability institutions in Assam, it is pertinent to provide a brief sketch as to how the whole disability affairs have been conducted by the government in the state. As mentioned in the previous chapter, at the national level under the Ministry of Social Justice and Empowerment, a separate department called Department of Disability Affairs was set up in the year 2012. But in the state of Assam till now no arrangement has been made for setting up a separate disability affairs department and therefore the entire disability affairs are being looked after by the Social Welfare Department of the government of Assam. Another nodal department authorized for issuing disability certificate is the Department of Health, Government of Assam. At present, Health Department and Social Welfare Department are the core government institutions in identifying and providing certain benefits to the persons with disability in Assam. After the implementation of PWD Act 1995 both these two departments are working collectively in identifying and issuing certificates to the persons with disability in the state of Assam. Initially, the Health Department conducted periodic medical boards at the district level for identifications of persons with disability and accordingly determine the percentage of disability in accordance with the government norms. It is mentioned in the chapter I(2)t of the PWD Act 1995 that forty percent is the minimum percentage of disability for the entitlement of disability certificate. On the basis of the medical report, the Social Welfare Department of the district provided an identity card and passbook to the persons with disability. In the recent past, certain modifications have been made by the government of Assam in the process of issuing disability certificates to the persons with disability. The Social Welfare Department now provides a particular format of disability certificate and after proper verification and examination by medical experts, the Joint Director of Health of a district is empowered to issue disability

certificate in the prescribed format. It is only the disability certificate holders who are entitled to get the benefit of various welfare schemes of the Government and other entitlements as mentioned in the PWD Act 1995 earlier and presently in the RPWD Act 2016. Both Social Welfare Department and Health Department collectively organize health camps and awareness programmes at district level for identification of disability and issuance of disability certificate at different parts of a particular district. The office of the state Disability Commissioner of the state was established as the quasi-judicial authority after the enactment of PWD Act 1995 in the state to ensure justice to the person with disability in case of any discrepancy. With the enactment of new disability law i.e., RPWD Act 2016, the government of Assam has also come out with state rules called the Rights of the Persons with Disability, Assam, 2018. As the RPWD Act itself is very comprehensive legislation, it has redefined the whole idea of disability and rearranged many things for disabled people. For instance, the new law has identified twenty-one types of disability instead of seven types of disability as identified by PWD Act 1995. The new act has also made the distinction between persons with disability and benchmark disability. According to RPWD Act 2016 'persons with disability' means a person with long term physical, mental, intellectual or sensory impairment, which in interaction with barriers, hinders his full and effective participation society equally with others, whereas person with benchmark disability means a person with not less than forty percent of a specified disability where specified disability has not been defined in miserable terms and includes a person with disability where specified has been defined in miserable terms as certified by the certifying authority. Of late the activities of the social welfare department have been separated into two categories, one is Directorate of Social Welfare (Women and Child Development Sector) and the other is Directorate of Social Welfare (Social Justice and Empowerment Sector). Presently, the disability affairs have been looking after by the Social Justice and Empowerment Sector, Directorate of Social Welfare. Since, the new law has been recently implemented in the state of Assam, many issues and institutions pertinent to the disability affairs have been in the transitional phase and the terms and conditions for the state commissioner for persons with disability has been modified in accordance with the RPWD Act 2016. It needs to be mentioned here that, the new law has made the provision for constitution of a State Advisory Board for Persons with Disabilities and

also a state committee for research on disability at the state level and a district level committee on disability to look after the disability affairs at the district level.

3.2.1: Types of Institutions pertinent to Disability in Assam:

- **State Departments and Statutory Body:**
 - Department of Social Welfare
 - Department of Health
 - State Commissioner for Persons with Disability
- **State-run Institutions:**
 - Composite Regional Centre for Skill Development, Rehabilitation and Empowerment of Persons with Disabilities
 - Vocational Rehabilitation Centres
 - District Disability Rehabilitation Centres
 - Govt BDS Deaf and Dumb School, Kahilipara, Guwahati
 - Jorhat Blind Institute, Jorhat
 - Society for Welfare of Blind, Guwahati, Kamrup Metro
 - School for Hearing Impaired, Kachajuli, Laluk, Lakhimpur
- **Non-Governmental Organizations:**
 - Shishu Sarothi, Ashadeep: A Mental Health Society, Swabalambi, Sahayika, Dhula Regional Physically Handicapped Association, Prerona: Spastic Society of Jorhat, Destination, AtmaNirbhar: Ek Challenge, UjoniAxomBikolango Bikash Somaj etc.



(Mapping of Institutions pertinent to disability in Assam, Source: Self-designed Mapping)

3.2.2 Assam State Advisory Board for Persons with Disabilities:

According to the Section 66 of the RPWD Act 2016, every state government shall by notification constitute a body to be known as State Advisory Board on Disability to exercise the powers conferred on and to perform the function assigned to it, under this act. The minister in charge of the Department in the State Government dealing with disability matters is the ex-officio chairperson and the Minister of State or the deputy minister in charge of the Department of disability affairs (if any) is the ex-officio vice chairman of the board. In Assam too, the state advisory body has been constituted by the state government under rule 34 to 44 of the State rules for the implementation of RPWD Act 2016. As the Social Welfare Department is the nodal department dealing with disability affairs in the state of Assam, hence the state government may designate the senior most secretary to the Social Welfare Department

as the member secretary of the board. In the section 71 of the RPWD Act 2016, the main functions of the State Advisory board are:

- a) The State Advisory Board shall be the State-level consultative and advisory body on disability matters and shall facilitate the continuous evolution of a comprehensive policy for the empowerment of persons with disabilities and the full enjoyment of rights.
- b) In particular and without prejudice to the generality of the foregoing provisions, the State Advisory Board on disability shall perform the functions, namely:
 - i) Advise the State Government on policies, programmes, legislation and projects with respect to disability;
 - ii) Develop a State policy to address issues concerning persons with disabilities;
 - iii) Review and coordinate the activities of all departments of the state government and other governmental and non-governmental organizations in the state which are dealing with matters relating to persons with disabilities;
 - iv) Take up the cause of persons with disabilities with the concerned authorities and the international organizations with a view to provide for schemes and projects for the persons with disabilities in the state plans;
 - v) Recommend steps to ensure accessibility, reasonable accommodation, non-discrimination for persons with disabilities, services and the built environment and their participation in social life on an equal basis with others;
 - vi) Monitor and evaluate the impact of laws, policies and programmes designed to achieve full participation of persons with disabilities;
 - vii) Such other functions as may be assigned from time to time by the state government.

3.2.3 State Committee for Research on Disability:

According to the new law, a State Committee for Research on Disability has been set up in the recent past consisting of the following members:

- i. An eminent person having vast experience related to disability affair or an eminent person having vast experience in the field science and research to be nominated by the state government as ex-officio chairperson.
- ii. Director of Health Services, Government of Assam as ex-officio member.
- iii. In-charge of the Composite Regional Centre under the Ministry of Social Justice and Empowerment as ex-officio member.
- iv. Director of Social Welfare, Government of Assam as ex-officio member.
- v. One expert in the field of medical and health nominated by the Government of Assam.
- vi. Six members from regional or state level organizations or individuals belonging to different categories of disability as nominated by the Government of Assam.
- vii. Chairperson or representative from the Assam State Women Commission
- viii. Chairperson or representative of the Commission for Protection of Child Rights.
- ix. Any other expert or special invitee that may be invited by the Chairperson.

The State Committee for Research on Disability shall with the approval of the state advisory board draft and forward schemes and policies for the implementation of the provisions of the act. Such schemes and policies shall be presented through the State Advisory Board for its consideration and adoption by the state government.

3.2.4 The District level Committee on Disability:

The district level committee on disability as mentioned in the Section 72 of the RPWD Act 2016 has been constituted in the different districts of the state. The members of the district committee are:

- i. Deputy Commissioner of the District as ex-officio chairperson.
- ii. District Social Welfare Officer as member.
- iii. Civil surgeon or chief medical officer as member.
- iv. Psychiatrist of the District Hospital as member.
- v. District Education Officer as member.
- vi. District Employment Officer as member.
- vii. Superintendent of the Police of the District as member.
- viii. Representative of the Public prosecutor of the District as member.
- ix. Two representatives from registered organization for persons with disability as members
- x. Two persons with disability as defined in Chapter I (s) of the RPWD Act 2016 as members.
- xi. District Officer dealing with the employment of persons with disability as member.
- xii. Any other member as nominated by the chairperson.

The main functions of the District level Committee are:

- i) Advise the district authorities on matters relating to rehabilitation and empowerment of persons with disability;
- ii) Monitor the implementation of the RPWD Act 2016 and rules made there under by the district authorities;
- iii) Assist the district authorities in implementation of schemes and programmes of the government for empowerment of persons with disabilities;
- iv) Perform as district level authority for appointment of limited guardianship for persons with disability as provided in Rule 8 of Assam State RPWD rules 2016;
- v) Look into complains relating to non-implementation of RPWD Act 2016 by the district authorities and recommend suitable remedial measures to the concerned authority to redress such complains.

3.3 State Commissioner for Persons with Disability:

The State Commissioner for Persons with Disability is a quasi-judicial body to look after the matters related with disability in the state of Assam. It has been set up under Section 60 of the PWD Act, 1995. The Chapter XII, Section 60(1) of the PWD Act 1995 mentions, “*the State Government may by notification, appoint a State Commissioner for persons with disabilities for the purpose of this Act*”. Further, under section 79 of the RPWD Act 2016 has also laid down same provision for the appointment of state commissioner for persons with disability. The state commissioner works under the supervision of Chief Commissioner of Disability, Ministry of Social Justice and Empowerment, Government of India. The qualification and other terms and conditions of the state commissioner for disability are listed below:

- i. A person having special knowledge or practical experience in respect of matters relating to rehabilitation can only become the state commissioner (Section 79(2) of RPWD Act 2016).*
- ii. The salary and allowances payable to and other terms and conditions of service (including pension, gratuity and other retirement benefits) of the State Commissioner shall be such as may be prescribed by the state government (Section 79(3,6) of RPWD Act 2016).*
- iii. The state commissioner shall be assisted by an advisory committee comprising of not more than five members drawn from the experts in the disability sector in such manner as may be prescribed by the state government (Section 79(7) of RPWD Act 2016).*

Again, Section 80 of the RPWD Act has specified the functions of the state disability commissioner as given below:

- i. Identify, suo motu or otherwise, provision of any law or policy, programme and procedures, which are in consistent with this Act, and recommend necessary corrective steps.*
- ii. Inquire, suo motu or otherwise deprivation of rights of persons with disabilities and safeguards available to them in respect of matters for which the State Government is the*

- appropriate Government and take up the matter with appropriate authorities for corrective action.*
- iii. Review the safeguards provided by or under this Act or any other law for the time being in force for the protection of rights of persons with disabilities and recommend measures for their effective implementation;*
 - iv. Review the factors that inhibit the enjoyment of rights of persons with disabilities and recommend appropriate remedial measures;*
 - v. Undertake and promote research in the field of the rights of persons with disabilities;*
 - vi. Promote awareness of the rights of persons with disabilities and the safeguards available for their protection;*
 - vii. Monitor implementation of the provisions of this Act and schemes, programmes meant for persons with disabilities;*
 - viii. Monitor utilization of funds disbursed by the State Government for the benefits of persons with disabilities; and*
 - ix. Perform such other functions as the State Government may assign.*

The Section 82 of the RPWD Act states that for the purpose of discharging the functions under the Act, the state commissioner shall have the same powers of civil court as are vested in a court under the Code of Civil Procedure, 1908 in respect of the following matters, namely:

- a) Summoning and enforcing the attendance of witnesses;*
- b) Requiring the discovery and production of any documents;*
- c) Requisitioning any public record or copy thereof from any court or office;*
- d) Receiving evidence on affidavits;*
- e) Issuing commissions for the examination of witnesses or documents.*

It is also mentioned in the subsection 2 of Section 82 of the RPWD Act, every proceeding before the state commissioner shall be judicial proceeding within the meaning of Section 193 and 228 of the Indian Penal Code and the State Commissioner shall be deemed to be civil court for the purposes of section 195 and Chapter XXVI of the Code of Criminal Procedure, 1973.

3.4 Composite Regional Centre for Skill Development, Rehabilitation and Empowerment of Persons with Disabilities:

The Composite Regional Centre (CRC hereinafter) for Skill Development, Rehabilitation and Empowerment of Persons with Disabilities, Guwahati, Assam was established by the Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment, Govt. of India to provide comprehensive rehabilitation services as well as promote development of human resources in the North-Eastern region. It came into existence from 19th March 2001 and is located at Guwahati Medical College Hospital (GMCH) Campus, Bhangagarh Guwahati, Assam. The centre works under the administrative control and supervision of Director, Swami Vivekanand National Institute of Rehabilitation Training and Research (SVNIRTAR) which provides technical and manpower support to CRC. The main objectives of the institute are listed below:

- In accordance with the socio-cultural background of the North East Region, it tries to deliver rehabilitation services.
- To provide services to the disabled persons, it conducts training and man-power development programmes. Training programmes are extended to rehabilitation professionals, village level workers, multi rehabilitation workers and other functionaries of government and non- government sectors.
- It is the resource centre for rehabilitation and special education of persons with disabilities of North East India.
- The centre also undertakes research and development with specific reference to the needs of diverse groups of people with disabilities in the North East Region.
- It also makes certain arrangements of designing, fabrication and fitment of aid and appliances for persons with disabilities.
- It conducts public education programme for creation of awareness in community.
- It tries to establish linkages for identification, assessment and service provisions of disabled persons with existing medical, educational and employment services.

- It tries to provide certain basic services to encourage the organizations, parents group and self-help groups associated with disability.
- It offers certain diploma courses to encourage human resources development.

Presently, CRC is running following four courses:

1. Diploma in Hearing Language and Speech
2. D.Ed Special Education (Mental Retardation)
3. Bachelor in Audiology, Speech Language, Pathology
4. B.Ed Special Education (Hearing Impairment)

Therapeutic and rehabilitation services for all types of disabilities are offered by CRC in its Out Patient Department (OPD). The OPD centre of CRC has following units:

- i) PMR unit
- ii) Speech and Hearing Unit
- iii) Physiotherapy Unit
- iv) Occupational Therapy Unit
- v) Prosthetics and Orthotics Unit
- vi) Clinical Psychology Unit
- vii) Special Education Services Unit
- viii) Orientation and Mobility Services Unit
- ix) Vocational Services Unit
- x) Mental Retardation Unit

CRC offers assistance to the persons with disability under Assistance to Disabled Persons for purchase/fitting of Aids and Appliances (ADIP hereinafter) scheme of Department of Empowerment of Persons with Disability under Ministry of Social Justice and Empowerment, Government of India. It is noteworthy to mention here that ADIP Scheme was initiated in the year 1981 with the objective to assist the needy disabled persons in procuring durable, sophisticated and scientifically manufactured, modern, standard aids and appliances for physical, social as well as psychological rehabilitation. Certain corrective surgeries wherever necessary are also conducted under

the scheme. A person with disabilities fulfilling following conditions would be eligible for assistance under ADIP Scheme.

- An Indian citizen of any age.
- Holds a 40% Disablement Certificate.
- Has monthly income from all sources not exceeding Rs.20,000.00 per month.
- In case of dependents, the income of parents/guardians should not exceed Rs.20,000.00 per month.
- The persons those have not received assistance during the last 3 years for the same purpose from any source. However, for children below 12 years of age, this limit would be one year.

The following table shows the amount of assistance to be provided by CRC under ADIP scheme:

Table 3.1: Amount of Assistance provided by CRC under ADIP Scheme:

Total Income	Amount of Assistance
Up to Rs.15,000/- per month	(I) Full cost of aid/appliance
Rs. 15,001/- to Rs.20,000/- per month	(II) 50% of the cost of aids/appliances

(Source: Official Website of CRC <http://crcguwahati.com>)

3.5 Vocational Rehabilitation Centre

Vocational Rehabilitation Centre (VRC hereinafter), Guwahati is one of the twenty-one rehabilitation centres established by Government of India in the year 1982 under Union Ministry of Labour, Directorate General of Employment and Training. The main purpose of the centre is to evaluate the capabilities of the disabled people and to provide comprehensive rehabilitation services. It offers services to the people belonging to five categories of disabilities viz. locomotor disability, visual impairment, hearing disability, mild mentally retarded persons, leprosy cured persons in NE region.

The VRC has the following objectives:

- *Vocational evaluation and adjustment of the physically handicapped persons.*
- *Assessment of the medical, psychological, rehabilitation needs.*
- *Assist in developing rehabilitation plans depending upon the specific needs.*
- *Sponsor physically handicapped registrants against notified/identified vacancies.*
- *Act as distribution centers for various schemes like Scholarship/aids and appliances.*
- *Make referrals to financial institution for funding self-employment ventures.*

As VRC was established for the employment and rehabilitation of disabled persons, it maintains the record of disabled people by registering their name for the purpose of employment in a particular format against reserved vacancies. After registration, an evaluation process is done through which the abilities and disabilities based on personal attributes are scientifically quantified with reference to their physical, mental, social & vocational capacities. This evaluation process helps the professional team to arrive at a suitable vocational diagnosis. Accordingly, a vocational plan is prepared depending on the individual's physical, mental, social and vocational capacities as well as socio-economic status of the concern person. The VRC conducts two types of training:

- i) **Formal training:** Formal training programmes of VRC are recognized by National Council for Vocational Training (NCVT) and Directorate General of Employment and Training (DGET). The qualified disabled persons can participate in formal training programmes.
- ii) **Non-formal training:** The non-formal training programme is for those disabled people who are not qualified to enter into the formal training programmes conducted by institute. Hence, VRC conducts certain non-formal training programmes such as basics in computer application, commercial practice, cutting, tailoring and embroidery, radio and TV mechanism, metal cutting and so on.

Besides, VRC also conducts certain Community Based Vocational Training (CBVT herein after) programmes in rural areas. CBVT's are organized at village and revenue circle level with the association of leading NGOs of the locality, District Rural Development Agency (DRDA hereinafter), Revenue Circle Office etc. to impart skills in accordance with the capabilities of the disabled persons. It needs to be mentioned here that VRC takes up special recruitment drives to fill up four percent of reservation vacancies exclusively hearing and visually challenged persons. VRC coordinates with the Department of Panchayat and Rural Development (PNRD), National Handicapped Finance and Development Corporation (NHFDC hereinafter), DRDA, nationalized banks, State Institute of Rural Development (SIRD), National Institute of Rural Development (NIRD), North Eastern Development Finance Corporation Ltd (NEDFI) and IIE (Indian Institute of Entrepreneurship) for assistance and support. Moreover, VRC also supports certain employment services which include job fairs, loan mela by NHFDC, setting up of Cooperatives, home bound employment, self-help group.

3.6 District Disability Rehabilitation Centres:

District Disability Rehabilitation Centre (DDRC hereinafter) for Persons with Disabilities is a scheme launched by the Ministry of Social Justice and Empowerment, Government of India in the year 2000. The main objective of DDRC is to provide rehabilitation services to the needy disabled people in accordance with PWD Act 1995. Along with comprehensive rehabilitation services for the disabled people, DDRCs act the basic information centre to create awareness among the people regarding the prevention as well as control of different types disabilities. The DDRCs also try to make convergence of schemes and programmes of various departments and mobilize them for the development of the persons with disabilities. It needs to be mentioned here that under the scheme DDRCs are established in different states of India at district levels in collaboration with state government and local NGOs. Presently, in Assam the following three DDRCs are in functional mode at state level which act as the nodal bodies of the DDRCs in different districts:

- a) District Disability Rehabilitation Centre, Assam Medical College, Dibrugarh, Assam

- b) District Disability Rehabilitation Centre, Silchar Medical College, Silchar, Assam
- c) District Disability Rehabilitation Centre, Abrita Hall, Adj.D.M. Bunglow, Tezpur, Sonitpur, Assam.

In addition to these, the Directorate of Social Welfare (Social Justice and Empowerment), Government of Assam has bestowed the responsibility to run DDRCs to certain NGOs in different districts of the state. The table given below shows the name of the NGOs and districts where DDRCs are located:

Table 3.2: List of DDRCs in Assam:

Sl No	Name of the District	Name of the NGO
1.	Barpeta	Kahar TarunShangha, Vill-Kahara, P.O- Sarupeta, Dist- Barpeta
2.	Bongaigaon	Sarvangi Bikash Trust, Bongaigaon, Majgaon, Bongaigaon
3.	Dhubri	North East Voluntary Association of Rural Development(NEVARD),College Road, Dhubri
4.	Hailakandi	Wodwichee, Lakhirband, Old Hospital Road, Hailakandi
5.	Jorhat	Prerona PratibandhiSishu Bikash Kendra, Cinamora, Jorhat
6.	Kamrup (M)	a) Help Aid, Sivam Hotel Complex, Dispur, Guwahati, Kamrup (M) b) Destination, Bhagadattapur, Kahilipara, Guwahati, Kamrup (M)
7.	Kamrup	Ashadeep, Bamungaon, Boko, Kamrup
8.	Nagaon	Gram Vikash Parishad, Rangoloo, Nagaon
9.	Sonitpur	North East Regional Multi-purpose School and Handicapped Training Centre, Balipukhuri, Sonitpur
10.	Lakhimpur	Dikrong Valley Environment &Rural Development Society, P.O.-Gosaibari, Narayanpur, Lakhimpur

Source: Official website of Social Welfare Department, Government of Assam, (www.socialjustice.assam.gov.in)

3.7: Special Schools under Government of Assam:

The Department of Social Welfare, Government of Assam has established a number of Special Schools for Students with Disabilities in different parts of the state. The list of the special schools is given below:

- Govt BDS Deaf and Dumb School, Kahilipara, Guwahati
- Jorhat Blind Institute, Jorhat
- Society for Welfare of Blind, Guwahati, Kamrup Metro
- School for Hearing Impaired, Kachajuli, Laluk, Lakhimpur
- Sreemanta Sarkar Mission, Barhampur, Nagaon
- Assam Sishu Vidyalaya, Bihpuria, Lakhimpur
- Janamangal Andha Adrasha Vidyalaya, Moranhat

Source: Official website of Social Welfare Department, Government of Assam, (www.socialjustice.assam.gov.in).

3.8: Non-governmental Organizations Pertinent to Disability in Assam:

It is worthwhile to mention here that the emergence of neo-liberal State not only implies the diminishment / reduction of the state sovereignty but also transfer of its responsibility to some other agencies. Hence, in the field of governance along with State institutions new actors, e.g., Non-Governmental Organizations (NGOs hereinafter) appear in the scene, which indicates the fundamental transformation in statehood and a new relation between state and civil society actors (Lemke, 2001.p11). Foucault equates this neo-liberal governmentality with multiple regimes of governance where the power relations in the society are restructured (Senellart and Foucault, 2008, p. 185). Therefore, it is essential to understand the role of NGOs in disability sector to which broadly conform to the laws and regulations made by the state while making their intervention.

3.8.1 Shishu Sarothi:

Shishu Sarothi, one of the leading non-governmental organizations in North East India working in disability sector was established in the year 1987. As an NGO it was registered under the Societies Registration Act 1860, Assam. At the initial stage, the NGO was started with just two children (Biki and Amit), a trained special educator and a close-knit team of parents and volunteers in one of the children's grandparent's house. In 1997, Shishu Sarothi was granted a piece of land by the Government of Assam at Birubari and it was shifted there. Shishu Sarothi offers services for children with cerebral palsy and multiple disabilities, conducts comprehensive training programs and tries to uphold the rights of persons with disabilities. Shishu Sarothi acts as the Centre for Special Education and its Outdoor Services for staff training and technical knowledge under the affiliation of the Indian Institute of Cerebral Palsy, Kolkata. Shishu Sarothi is also the Zonal Coordination Committee for the Rehabilitation Council of India (RCI), and is a State Nodal Agency Centre for the National Trust. In addition, it is an active member of the Disability Rights Group and other national level advocacy bodies. Hence, the main vision of Shishu Sarothi is to create an inclusive world where children and persons with disabilities have equal opportunities and are empowered to participate freely and live their lives with dignity and respect. Therefore, the NGO tries to uphold and advocate for rights of children and persons with disabilities, ensure equal opportunities and promote their inclusion and active participation in a non-discriminating barrier free environment.

The following are the main objectives of Shishu Sarothi:

- *For the inclusion and full participation of children and persons with disabilities in the society, the NGO's objective is to facilitate the accessibility for appropriate and innovative therapies and interventions.*
- *For the deeper understanding of the issue of disability Shishu Sarothi's objective is to create a cadre of trained human resources and undertake research studies to build knowledge and understanding about disability in general and Cerebral Palsy and developmental disabilities in particular.*

- *Sensitization of all stakeholders, ensure implementation of different disability legislations, facilitate redressal of grievances etc. also include in the objectives of ShishuSarothi.*

Units of Shishu Sarothi :

- **Centre for Inclusive and Vocational Education:** The Centre for Inclusive and Vocational Education (CIVE hereinafter) of Shishu Sarothi is a school with inclusive approach. The basic objective of CIVE is to provide all round special educational and therapeutic inputs to the children with disabilities. In the centre, Individualized Educational Programmes (IEP) are drawn up for each child with periodic evaluation. Efforts are also made for the active participation of the parents by involving them throughout the learning process. Multi-sensory and low-cost teaching learning materials are designed for more effective teaching and learning experiences. Along with child specific curriculum, co-curricular activities are also taught in the centre.
- **Early Intervention Unit (EIU):** The EIU offers services not only for early detection, screening and management of high-risk babies and infants but also assesses them for delays in different developmental aspects such as motor, language, cognitive, self-help and social skills. To stimulate the developmental functioning of the children, different play way methods are used. EIU has also the provision of a home-based program, where regular follow-ups are to be done by the parents. The Early Intervention Unit (EIU hereinafter) of Shishu Sarothi works hand in hand with CRC, Guwahati. Besides, Shishu Sarothi's EIU is also supported by Com DEALL Trust, Bangalore. A team of professionals like speech language pathologist, occupational therapist, physiotherapist, developmental psychologist and educators have prepared an individualized therapy schedule for this programme.
- **The Information and Communication Technology Laboratory (ICT LAB):** The Information and Communication Technology Laboratory (ICT LAB hereinafter) aims at imparting comprehensive computer aided training

programmes for the children with disabilities. To make proficient in basic application of computer, special softwares are also provided to the students according to their individual needs.

- **Human Resource Development Division (HRD):**The training and Human Resource Development division runs training programmes approved by the Rehabilitation Council of India, (Ministry of Social Justice & Empowerment, Government of India). The basic objective of different training programmes under this division is to create a cadre of trained rehabilitation professionals, thereby ensuring availability of better quality of services for persons with disabilities in the region. The courses which are offered under this division are as follows:

Table 3.3: Courses offered by Shishu Sarothi under Human Resource Development Division:

Sl No.	Course	Criteria	Duration	University	Mode	Session	Fees
1.	Diploma in Special Education- Cerebral Palsy (DSE-CP)	10+2 (50%)	2 years	NIEPMD	Regular	April- May	2000/pa

Source: Field survey

- **Counseling Unit of Shishu Sarothi:** The basic objective of Counseling unit of Shishu Sarothi is to impart knowledge about the psycho social aspects related to disability so that the parents can understand the special needs of their child and cope and manage the situation. For creating awareness about disability, the unit promotes school awareness programs, provides counseling to the parents through individual and group sessions and conducts workshops on stress management of parents. To meet the immediate needs

of children with disability, the unit also tries to build up some networks with other organizations working in the field of disability for allocating resources.

- **Disability Law Unit-North East (Dlu-Ne):**The main objective of DLU-NE is to create awareness both socially and legally regarding the rights of person with disabilities through advocacy and activism. It helps the disabled persons not only in filing litigation but also conducts certain sensitization programmes at local level. The unit also advocates for policy changes so as to protect the rights of persons with disabilities enshrined in various laws of the country and ensures their assimilation in mainstream society.
- **Disability Employment Initiative (DEI):**The Disability Employment Initiative works towards economic empowerment of persons with disabilities in the state and the North Eastern region. It facilitates the disabled persons only in access to employment opportunities both in the public and private sectors, but also in the field of self-employment activities and livelihoods.
- **State Nodal Agency Centre (SNAC) for the National Trust:**Sishu Sarothi is the State Nodal Agency Centre for the National Trust for Assam and Arunachal Pradesh. As mentioned in the previous chapter, National Trust is a statutory body under Ministry of Social Justice and Empowerment, Government of India, for the welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities.
- **Bharti Infratel Scholarship Programme:**In March 2016 with support from Bharti Infratel Limited (one of the largest telecom tower infrastructure providers in India), Shishu Sarothi has launched a scholarship programme to provide financial support to students with disabilities for pursuing higher education. This scholarship program is designed to benefit students across the eight states of the Northeast viz: Assam, Manipur, Mizoram, Nagaland, Sikkim, Arunachal Pradesh, Tripura and Meghalaya.
- **Sense International India - Educational and Rehabilitation Services for Deaf blind And Multi-Sensory Impaired Population:**Shishu Sarothi has initiated a project in partnership with Sense (International) mainly to reach out to the Deaf and blind population, including children (0-14 years) and

adults, in Kamrup district (Metro and Rural). The main objectives of the project include identification, assessment, intervention at individual level.

3.8.2 Ashadeep: A Mental Health Society-

Ashadeep, an NGO was formed by Anjana Goswami and Mukul Chandra Goswami with some like-minded people in the year 1996 at Guwahati. The basic objective behind the formation of the NGO was to initiate and strengthen interventions for persons with mental disorders and their families in the North Eastern states of India. It needs to be mentioned here that for the people suffering from mental health issues, no rehabilitation facilities were available in Assam as well as in entire North Eastern region at that point of time and the patients had to visit either Kolkata or Bangalore which was not affordable for all. With a traumatic experience of taking care and rehabilitating own sister suffering from Schizophrenia for ten years, the founder Mukul Chandra Goswami (banker by profession till 2001) along with his wife Anjana Goswami (lecturer by profession) realized the need of an organization for the rehabilitation of the people suffering from mental health issues.

Units of Ashadeep: A Mental Health Society-

- **Ashadeep Day Rehabilitation Centre:** The Day Rehabilitation Centre of Ashadeep offers the basic life skills to the individuals with intellectual disability and associated disorders and persons recovering from mental illness for daily living. Learning through role plays and peer training methods are followed by the centre for different types of activities like functional academics, prevocational activities, sports and music along with conventional academics. Based on their level of retardation every student is provided an individualized intervention plan along with a six-monthly goal. Drama, speech, movement and yoga therapies are also considered as parts of the rehabilitation process. Based on their capabilities, special trainings on sports are also conducted among the students with intellectual disabilities so that they can compete at different level

of sports forum. Accordingly, trained students are also registered as a special athlete under Special Olympic Bharat. Individual and group counseling for reintroducing social skills like interpersonal and communication skills are also provided on regular intervals for the persons recovering from any kind of mental illness. Vocational training in block printing, candle making, jute products making, food processing and products made with waste etc. are also provided.

- **Rehabilitation of Homeless Persons with Mental Illness:** Ashadeep has the facility of two rehabilitation houses for Homeless Persons with mental illness viz. Udayan for the male and Navachetana for the female. The basic objective of these houses is to provide the opportunity of recreating the life of mentally ill people which was lost due to the illness. Ashadeep established Navachetana Rehabilitation Homes for Homeless Women with Mental Illness in 2005 with support from Sir Ratan Tata Trust. In 2013, the Government of Assam collaborated with Ashadeep for establishing a 40 bedded rehabilitation home- 'Udayan' for homeless men with mental illness. These rehabilitation houses primarily offer care, treatment and rehabilitation measures to the homeless women and men with mental illness peripatetic in the streets. It needs to be mentioned here that the rehabilitation process of Ashadeep includes the reunion of the person with her/his family and reintegration with the community. Vocational training and skill building are also provided as a part of the rehabilitation process which can help the bordersto earn a livelihood after their discharge instead of being considered as burden to their families. To ensure that the discharged persons are continuing their treatment follow up is also continued by the organization. It needs to be mentioned here that Ashadeep has reintegrated disabled people with their families residing in various states like Andhra Pradesh, Arunachal Pradesh, Tripura, Gujrat, Haryana, Madhya Pradesh, West Bengal, Bihar, Karnataka, and Meghalaya.
- **Home Again: Independent Shared Housing in the Community for residents of Navachetna and Udayan:** Ashadeep has the facility of 'Home again'-- refers to the independent set up of shared houses for those people who cannot be re-

integrated after reducing their positive symptoms related to their illness and better functional level due to certain other reasons. The organization has three urban homes at Rehabari and Japorigog, Guwahati and three Rural homes at P.L. Home Campus, Bamunigaon, where five persons can live in each shared house.

- **Psychiatric Outdoor Clinic:** Ashadeep is also running a Psychiatric Outdoor Clinic at Ulubari, Guwahati for the followup treatment of the reintegrated residents of Navachetna and Udayan. On every Tuesday, consultation is provided in this outdoor clinic.
- **Community Mental Health Programme:** Ashadeep started outreach mental health camps i.e., the Community Mental Health Programme in the year 2012 in one block each in the districts of Darrang, Morigaon and Kamrup (Rural). The main objective of the programme was to identify and intervene mental health issues at the community level. Homebased treatment was provided to the people having mental health issues with infrastructural support from Government Block Public Health Centres. The programme was funded by Tata Trust and could intervene 1906 persons in three blocks during the period 2012-2016.

3.8.3 Swabalambi: Society for Rehabilitation and Training of Persons with Multiple Disabilities:

Swabalambi is an NGO based on Community Based Rehabilitation (CBR hereinafter) working for equalization of opportunities and Rights and inclusion/mainstreaming of all disabled people within their communities since 1990s. CBR is a World Health Organization's initiative for the promotion inclusive development based on multi sectoral, cross disability and human rights approach which includes for example, equal access to health care, education, skill training, employment, family life, social mobility and political environment (https://cbr-network.org/?page_id=123). For development at the community level, CBR involves

persons with disabilities, their families, community and different organizations of the society. As one of the pioneers of community-based organization in Assam, Swabalambi tries to ensure basic essentials of life such as Health, Education, livelihood to the people with disabilities along with their families.

The basic objectives of the organization are:

- Inclusive development of the community where emphasis is given on disabled members along with others.
- Uplift the living conditions of families belonging to SC, ST, OBC and BPL (Below Poverty Line).
- Promote social integration, equalization of opportunities, and rehabilitation for people with disabilities.
- Special focus on the issue of gender and disability.

Swabalambi adopts an alternative model of community-based programme especially in rural areas which consists of local coordinator, panel of resource persons, community support and disabled peoples' organization.

Local Coordinator: A CBR worker and field staff are appointed from among the community as local coordinators for 1-2 Gaon Panchayat. The main activities of the local coordinators are to conduct household surveys in the allotted areas and identify the number and categories of disabled persons.

Panel of resource persons: The panel of resource persons conducts certain training programmes for the CBR workers and field staffs. The training programmes include the areas like inclusive health approach as well as home-based interventions so that the CBR workers and field staffs can provide adequate services to the people with severe disabilities.

Community support: Community support is the most integral part of the CBR process. Therefore, the CBR staffs organize various programmes with different stakeholders and local leaders to sensitize them on disability issues. In the process of community support, an effort has also been made to ensure full participation of all the members of the community to sustain certain interventions on rehabilitative measures.

Disabled Peoples' Organizations: To provide a platform for disabled people Swabalambi forms certain disabled peoples' organizations at village, panchayat and block level. The CBR workers and field staffs coordinate with these organizations for certain rehabilitative interventions.

The main areas of intervention by Swabalambi are health, education, livelihood and empowerment of the local community. It undertakes certain activities not only to reduce the occurrence of disability, but also to improve the functional abilities of the disabled people and experience qualitative change in their lives. These activities involve:

- Regular meetings with different stake holders of a village to provide a correct understanding of the issue of disability, rehabilitation and inclusion.
- Project Personnel's visit to health centres at the local to identify available resources for preventive, rehabilitative and curative needs of disabled people.
- Plan for Home based intervention and start identification of barriers at different levels.
- Organize Disability Certification Camp at the project area or at the Government Hospitals.
- Children with Disabilities are provided home based education so that they get admission in Primary schools of their respective villages.
- Training programmes are conducted for the teachers of primary, middle and higher school teachers on Disability and issues for equal participation and learning.
- Preparation of teaching and learning materials to the teachers in Primary Schools for enabling inclusive education for disabled (IED).
- Scholarship to children with disabilities (CWDs) as well as SC/ST students.
- Development of Livelihood skills of the disabled persons as well as the non-disabled population in the villages.

3.8.4 Sahayika:

Sahayika Child Guidance Centre, Guwahati was founded by Mrs. Kalpana Bezboruah, a child psychologist and social worker in the year 1986. The main vision of Sahayika includes socio-emotional development of children with special needs. The organization mainly covers the disabled children suffering from Autism, Hearing and Speech Impairment, Mental Challenges etc. The programmes of Sahayika are as follows:

Special School: Sahayika runs a special school for the students with intellectual disabilities. By merging both formal and non-formal mode of schooling, the school adopts the philosophy of alternative schooling with specialized training, specialized guidance and Individual Education Plans (IEPs hereinafter). Based on the child's developmental age, current level of functioning and the type of disability IEPs are prepared. Each IEP is highly structured, goal oriented and outcome focused and special emphasis is given on music, art, dance, handicrafts and other artistic activities which enable for flow of expression, inner harmony and creativity. Yoga and physical exercise, speech therapy and other specialized therapies are also considered as a part of IEP.

Infancy and Early Child Intervention Programme: Infancy and Early Childhood Interventions Programme is designed for the children with developmental delays and those who are at risk for cognitive impairment. Movements, self-help skills (such as eating, grooming, dressing, toilet training, communication) speech and language development, social interaction and pre-academic skills etc. are imparted under this programme.

Therapeutic Treatment and Individual Fitness Program (IFP): The programme aims at improving overall health as well as lowering their anxiety and developing the confidence level of the children suffering from autism. The organization tries to provide therapeutic treatment to these children after scientific assessment and identifying the specific issues with communication like voice disorder, stammering, stuttering, late speaking etc. Auditory training is also conducted for all hearing-impaired students. Besides, based on

individual assessment and other inputs from the special educators, the organization provides one on one training utilizing Individual Fitness Program (IFP) that are specifically designed for each autistic beneficiary. Special emphasis is given on coordination, balancing, eye-hand coordination and gross motor skills.

Pre-Vocational Training Programme: Pre-vocational training of the organization includes tailoring and embroidery, eco-friendly handicraft products and decorative diyas.

Additional Services: The organization renders a number of additional services including counseling therapy, remedial education therapy, training and research in the field of disability and various out-reach programme to create awareness among the people of different parts of Assam.

3.8.5 Dhula Regional Physically Handicapped Development Association:

Dhula Regional Physically Handicapped Development Association was established in the year 1990 at Dhula of Darrang District of Assam. The organization works for the socio-economic development of society and all-round development for persons with disabilities, needy poor widows and orphan child, adopted women and neglected children by the family members.

The following are the main activities of Dhula Regional Physically Handicapped Development Association:

Half Way Home for Psycho-Social Rehabilitation of Treated and Controlled Mentally Ill Person: Under this project the organization provides rehabilitation services to the mentally ill people along with proper medical treatment. Residential facility is also available in the organization for such kind of people and takes the residents to Tezpur Mental Hospital on periodic basis for proper evaluation of their

health condition. Along with prolonged treatment process, efforts are also made to provide certain vocational training to the mentally ill people and their families.

Special School cum Vocational Training Centre for Handicapped: The organization runs a special school for hearing impaired students and conducts certain vocational training programmes including tailoring, weaving and other handicraft materials.

Child Care Initiative: Under this scheme, the institute provides all kinds of pre-schooling facilities and day care services mainly for the hearing-impaired children with appropriate therapeutic treatment for their early intervention.

Senior Citizen Home: The organization also has the facility of old age home for the homeless persons above 60 years. Certain recreational facilities are available within the campus of the institute for them.

Orphanage: The institute has the facility of orphanage mainly for the street children.

UJJAWALA (A Comprehensive Scheme for Prevention, Rehabilitation, Rescue and Reintegration of Victims of Trafficking for Commercial Sexual Exploitation): Under this scheme, the organization tries to rescue the victims of trafficking for commercial sexual exploitation and provides them certain psycho-social rehabilitation along with some vocational training.

3.8.5 Prerona-Spastic Society of Jorhat:

Prerona-the Spastic Society (Prerona hereinafter) of Jorhat established in the year 1992 as a non-governmental organization working for persons with disabilities in the Jorhat District of Assam. The organization is registered under Societies Registration Act 1860, Person with Disability Act 1995 and National Trust Act 1999. It is a RCI recognized organization and affiliated to Indian Institute of Cerebral Palsy Calcutta. Additionally, Prerona conducts certain rehabilitation programmes for people with different types of disabilities. Initially, the founder director of Prerona Ms. Sayera Rahman started a small school in her house with few students as her second child born

with cerebral palsy. Presently, Prerona conducts different programmes like Early intervention program, Centre for Special Education, Vocational training centre, Vocational Training Programme under Prime Minister National Council Skill Development Programme, District Disability Rehabilitation Centre, Half Way Home for Psycho-Social Rehabilitation of Treated and Controlled for Homeless Mentally ill Person and Community Based Rehabilitation.

The following are the objectives of Prerona:

- Prerona tries to develop certain basic and sustainable life skills among the persons with disabilities.
- The organization endeavours to create awareness among parents and other persons of the society about the rights of the persons with disabilities.

The following are the various activities of the organization:

Early intervention programme: Early intervention programme is designed for the children who are at risk or have developmental delays within the age group of 0-3 years. Each and every child provides individualized intervention which includes physiotherapy, speech & language therapy, child development & family intervention.

Centre for Special Education: The centre for special education accommodates the children with Cerebral Palsy, Mental Retardation, Hearing Impairment, and autism. Based on the level of functioning, skill trainings are provided in various areas such as self-help skills, gross and fine motor skills, functional reading and writing skills, and cognitive skills. Along with Computer assisted training modules, various learning aids and appliances are also being utilized for needy students.

Vocational Training centre: The training programmes under Vocational Training Centre are designed for the adults with multiple disabilities. Training on embroidery, handicraft, file making, art & craft, music etc. are provided to the adult disabled. Besides, different training programme are also organized for NGOs working for disabilities, SSA teachers, Anganwadi Workers, ASHA workers etc. Prerona also

conducts certain orientation programme on Special Education in other educational institutions including colleges and schools.

Respite Care Centre: Prerona provides residential services for both short term (respite care) and long term (prolonged care) for persons with Autism , Cerebral Palsy , Mental Retardation & Multiple Handicapped residents under a scheme called Samarth Scheme..

District Disability Rehabilitation Centre: Prerona is the nodal institute of DDRC for Jorhat District. Under this scheme physiotherapy, speech therapy, medical science, Distribution of Aids and Appliances, Awareness programme, orientation for teachers and family etc. are regularly done by the organization.

National Institute for Open School: Prerona is a centre for open schooling affiliated to Special Accredited Institution of Education of the Disadvantages (SAIED).

Half Way Home for Psycho-Social Rehabilitation of Treated and Controlled for Homeless: Under this scheme, the mentally ill people are rescued and reintegrated with their families.

Community Rehabilitation Programme: The activities under this scheme are as follows:

- Home Management and visit by therapist: Prerona mainly targets the BPL people under this programme where an effort has been made to provide certain essential services including regular visits of the therapists to the needy households. Apart from therapists, some of the social workers of the organization regularly visit the households to make aware about the issues associated with disease and disability. Counseling is also provided at individual level to all the family members of a disabled person to make them aware about different medical as well as social dimensions of disability.

- School visits: The social workers of Prerona also visit regular schools to create awareness among teachers and students about the issue of disability. They also try to provide some extra supports to the needy children with disabilities.

3.8.6 Destination (A Real Home for Persons/children with special need):

Destination (A Real Home for Persons/children with special need) is an NGO established in the year 2005 under the Society Registration Act 1986. It is located in Kahilipara, Guwahati Assam. Destination tries to provide welfare services to the mentally challenged persons specially those who are homeless. It has the facility of residential rehabilitation services of different age groups starting from 3 years. The organization has 22 full time staffs and 5 full time volunteers. It also works as a DDRC of Kamrup (M) district under the DDRC scheme of Ministry of Social Justice and Empowerment, Government of India.

3.8.7 Atma Nirbhar: Ek Challenge:

Atma Nirbhar: Ek Challenge is an NGO formed by Mr. Kaushik Das with the objective to provide economic rehabilitation and to create employment opportunities for the persons with disabilities in 1996 at Guwahati, Assam. The organization is registered under 80G of the IT Act and FCRA. The organization has been initiated different 'not-for-profit', disabled-friendly, income-generating activities / projects. Packaging of tea and grocery items are the main activities of the NGO mainly done by the disabled people. By involving such activities a few disabled persons are getting the opportunity to work with dignity and earn a living. The NGO is the recipient of the national awards for promotion of employment of the disabled like the *Helen Keller Award* awarded by National Centre for Promotion of Employment for Disabled People (NCPEDP) in 2000 and 2020 and the 'National Award for the Welfare of Persons with Disabilities – 2004'.

3.9 Conclusion:

The above discussion reveals that with the enactment of new disability legislation, a growing consciousness has been witnessed on the issue of disability at the societal level and the proliferation of number of institutions pertinent to disability has been seen in the state of Assam. The policies and programmes adopted by the State for mainstreaming persons with disability is of course a welcome development that may pave the way for deconstruction of stigma and stereotypical notions associated with disability. However, there is always a huge gap between ideals and execution. It is the institution that materializes the ideals and the goals that has been set in different programmes and policies of the government. Hence, the level of implementation of policies and programmes depends upon the performance of the institutions. At the same time, the governmentality aspect of the institutions is of course essential while analyzing the functions of an institution, as it reveals the techniques of governing a particular section of the society and maintaining legitimacy of the system. The present chapter only provides a brief profile of the institutions pertinent to disability. The proceeding chapters will reveal the functioning part of the institutions and their role in addressing the issue of disability in the state of Assam.

CHAPTER IV

FUNCTIONING OF THE STATE INSTITUTIONS RELATED TO DISABILITY IN ASSAM: AN EMPIRICAL INVESTIGATION

4.1: Introduction:

Characteristically Indian State is a welfare state that has constitutionally expressed its commitment for the collective wellbeing of the people. Article 41 of the constitution of India under the directive principles of state policies mentions about the role of the State towards providing public assistance in cases of unemployment, old age, sickness, disablement and so on. In the field of disability, Government of India has passed certain legislations at different point of time such as Mental Health Act 1987, Rehabilitation Council of India Act 1992, PWD Act 1995 and more recently RPWD Act 2016. However, at the policy level disability does not assume much significance in the post-independent period. In a state like Assam where economic backwardness, lack of industrialization, natural calamities like flood, continuous political disorder due to insurgency and many more are profound, disability remains as a less significant issue in the public domain. Even in the human rights discourse too, disability has been remained as an excluded agenda in the region, because of its preoccupation with police atrocities, army operations against insurgency, rights of the political prisoners, victims of the violent conflict etc.

All the major developments pertinent to disability took place only after the enactment of PWD Act 1995. Accordingly, the Government of Assam bestowed upon the responsibility to the Social Welfare Department to look after the issues pertinent to disability. As mentioned in the third chapter, in the state of Assam the disability governance has been associated with two government departments viz., the Department of Social Welfare and the Health Department and one statutory body i.e., the State Commissioner for the Persons with Disability. The Health Department identifies the

identifies the category and the percentage of disability and the Department of Social Welfare implements the various policies and programmes pertaining to it. The present chapter makes an attempt to carry out an empirical investigation regarding the role of these two Departments and the statutory body in addressing the issue of disability in Assam. Besides, some of the scheme beneficiaries were also interviewed. As regards the selection of schemes, two schemes viz. Scheme for Rehabilitation Grant and Scheme for scholarship to the students pursuing technical and medical education were selected for empirical investigation. The data available in the Directorate of Social Welfare, Government of Assam shows that the highest number of the selected scheme beneficiaries are found in Jorhat District and Kamrup (M) district. Hence, these two districts have been selected for empirical investigation. The field study was conducted approximately from June 2017 to June 2019.

4.2: Responses from the Department of Health, Government of Assam:

It is noteworthy to mention here that governance of disability is possible when proper identification and codification is done by the concerned authority. As instructed in the PWD Act 1995 the percentage of disability for obtaining a disability certificate has been determined by a medical board at district level hospital. However, in recent times no medical board is required for issuing certificate. The joint director of Health services of the concerned district is empowered to issue disability certificate after proper verification and examination by the medical experts. Hence, the joint director of health services at the district level is accountable for determination of the percentage of disability of a person. Therefore, joint directors of the concerned districts are interviewed for the purpose of empirical investigation. Besides, during the field investigation a gap had been identified between the disability certificate holders and total number of disabled populations. According to the Census 2011, the total number of disabled persons in the state of Assam is 4,80,065 and the following table shows the year wise number of disabled certificate holders.

Table 4.1: Year wise number of Disability Certificate Holders

Year	No of Disability Certificate holders
2016	3,00,038
2017	3,23,000
2018	3,65,078
2019	3,90,090

Source: Directorate of Health Service, Government of Assam

Responses of the Joint Directors:

- All the respondents have pointed out that having a disability certificate is important for each and every disabled person to avail different schemes of the government.
- As mentioned in the previous chapter, earlier disability certificate was issued in accordance with PWD Act 1995 and presently with the enactment of RPWD Act 2016 the process has been changed including the format of the certificate. As of now, the Social Welfare Department provides only the form for disability certificate and after proper verification the Joint director of a concern district issue disability certificate. Besides, the respondents highlighted the fact that the RPWD Act 2016 has extended the types of disability to twenty-one types which was earlier seven in number according to the PWD Act 1995. For example, persons suffering from epilepsy, parkinsons' disease, haemophilia, thalassemia, sickle cell disease etc are also considered as categories of disability. However, it is come to know from the interviews that proper medical experts have not been appointed in many district hospitals of Assam and also adequate infrastructure and appropriate technology are also not found to be available to identify some of the newly included categories of disability.
- However, the respondents have mentioned about some positive aspects of the certificate issue process. Earlier, medical board was held once in a month, the certificates are provided to the applicants on that particular date. Presently, the

disabled persons need not to wait for the medical board as with the proper examination by the experts on particular medical condition and if the condition of disability is above forty percent and more as mentioned in the RPWD Act 2016, immediately certificate can be provided to the disabled persons.

- In the state of Assam, the question of citizenship has remained as a burning issue for several decades together. It is needless to mention that Assamese identity has been marked by the xenophobia of illegal immigration from foreign countries particularly from Bangladesh. It has certain implications even in the whole process of issuing disability certificate. One of the joint directors informed that the number of applicants seeking disability certificate is relatively higher among the minority communities, hence the health authority at times also seeks the voter identification card or other relevant documents that proves the Indian citizenship from the applicant or the parents of the applicants while issuing disability certificate.
- The respondents also mentioned about the health camps organized in different areas of a district. Generally, health camps are organized by the Social Welfare Department in association with some local NGOs working in the field of disability. The main objectives of the health camp are not only to identify disabled population in a particular locality but also to create awareness about the rights of disabled people. Although all the respondents have pointed out that health camp is an effective mechanism in identifying disabled population, but they cannot provide certificate in the camps as proper examination of the medical condition is not possible in the camps.
- The respondents highlighted the rural urban disparity while expressing the level of awareness regarding the various government benefits for the persons with disability. Therefore, in urban areas the participation of the disabled persons in the health camps for issuing disability certificate is relatively higher than rural areas.

4.3 Responses from the Department of Social Welfare, Government of Assam:

As the Social Welfare Department is the nodal department for the implementation of various policies and schemes of the government, a few office bearers viz. director, joint director, office assistant at different level are interviewed to know the initiatives for the persons with disability on the part of the government and also to know about the level of implementation of those policies.

- The respondents have mentioned that social welfare department is an integrated department where along with disability affairs, women, child and other marginalized sections of the society are also included under their purview. Hence, sometimes they are unable to pay full concentration on disability issue. The respondents also referred to the RPWD Act 2016, according to which there should a separate department for Disability Affairs in the state.
- As informed by one of the officials of Social Welfare Department, although there are a number of schemes available for the disabled people, the government specifies a particular time frame for applying those schemes on yearly basis. For example, the time for applying Deendayal Pension Scheme was the month of July in 2019, which was changed by the government to March 2020. Therefore, it becomes difficult for the disabled people to get proper information as well as benefits of different schemes of the government.
- The respondents also informed certain issues relating to the health camps for identifying disabled people. As identification part is done by the Health Department, the Social Welfare Department has to depend on the consent of the doctors and other health workers for organizing such health camps. Sometimes, it seems that as the health Department is not accountable to Social Welfare Department, hence a proper coordination is lacking between the two Government departments. As times, as informed by the respondents many doctors leave the health camps much before the actual time frame of the health camp.
- Another important point raised by one of the respondents is the issue of percentage of disability. It needs to be mentioned here that the RPWD Act 2016

has specified forty percent of disability as benchmarked disability and those will be entitled to get benefits of the different government schemes pertinent to disability. On the other hand, persons less than forty percent are considered as only persons with disability. In such a situation, whenever a person with disability is not being recognized as benchmarked disabled in a particular health camp, he/ she again applies for the same in another health camp only to get increased the percentage of disability. In such cases both the Health Department or Social Welfare Department till now do not have any proper database to recognize such persons who apply disability certificate twice or thrice in such health camps.

- One respondent has mentioned that although the Social Welfare Department is responsible for implementing all the Government schemes for persons with disability, they do not have any role to provide disability certificate expect organizing different health camps for identifying those people.
- The field investigation has revealed that recently the Government of India has initiated the provision of unique identity card for disabled persons. Accordingly, the reports on nature and percentage of disability provided by the doctors are needed to be uploaded in the website of the central government (www.swavlambancard.gov.in) for getting a unique identity card for disabled persons that will serve the purpose throughout the country. The stakeholders of the social welfare department also mentioned that many persons with disability from different background are not well equipped to handle websites or other digital devices. Hence, many of them have been deprived from getting a unique identity card. A number of respondents even put the opinion that compared to the newly introduced digital system, the earlier offline system was relatively better, more accessible and disabled friendly.

4.4 Responses from the state Disability Commissioner:

As stated earlier, the disability commissioner is the quasi-judicial body that has been set up at the state level after the enactment of the PWD Act 1995 to look after the disability affairs. The State Disability Commissioner is appointed by the state government from the civil servants of the state. He is entrusted with the responsibility to intervene in the areas where deprivation of the rights of persons with disability takes place. The commissioner can initiate either suo moto case or the victims can also give complaints. Hence, the state Disability Commissioner is a core institutional apparatus of the state that needs to be address while understanding the issue of disability related institutions in a particular state. For that matter an informal interview was conducted with the Disability Commissioner. The summary of the interview has been given below:

- The Disability Commissioner informed the initiatives in the field of employment as well as admission in different educational institutions in accordance with the recent Act i.e RPWD Act 2016. However, it was mentioned by the commissioner that although the office of the state disability commissioner has been established as a quasi-judicial body, it has certain limitations. For example, the commissioner can only give directions to the concerned authority for the protection of disability rights as well as reasonable accommodations of them. It does not have any executive capacity to enforce any public/private agencies to implement any disability scheme or policy.
- In the PWD Act 1995 and RPWD Act 2016, various provisions have been enshrined regarding the judicial power of the state commissioners to ensure the rights of the persons with disability. However, it has been observed the state disability commissioners who have been appointed so far have mainly come from civil service cadre. At times, in most of the cases state commissioner for disability is a term post and the civil service cadres have been appointed in this position in the middle of their career. In such a situation it has come to know from the informal conversation that the junior civil servant cadres who may be appointed as a State Disability Commissioner often unwilling or reluctant to give any direction on any issue pertinent to disability to a senior officer appointed in different Departments of the government.

- The commissioner also pointed out that for a barrier free environment there must be coordination among the different departments of the government. For example, for transportation facilities along with well equipped vehicles, the road conditions must also be improved. Hence, Transport Department and Public works Department should work together for making public transportation accessible for the disables.
- As stated earlier the issue of disability is a highly complex and multi-dimensional phenomenon. For understanding the issue of disability, it requires continuous involvement and proper training. Most of the commissioners coming from different bureaucratic background have been appointed in this position for a very short span of time. Once they acquire some knowledge about disability, they have been shifted to another Department. In such a situation it seems that the Office of the Disability Commissioner is just an ornamental institution established only to fulfill the provisions of the disability legislations rather than serving the real purpose of the disability community of the greater society.

4.5 An Overview of the Government's Schemes Pertinent to Disability in Assam:

Like other marginalized caste, class or gender groups, certain kind of affirmative actions are also essential for persons with disability for their full and meaningful participation in the society. As mentioned in the previous chapter, the medical model of disability basically centered around to cure impairment of a person with disability. But whenever medical initiatives fail to offer a cure than rehabilitation or necessary measures are to be extended to the educational and occupational areas of life of the impaired persons in order to normalize their functions. In such a philosophical backdrop, both the central government as well as various state governments of India have initiated certain schemes for the wellbeing of the persons with disability from time to time. As the present study is only confined to understand the role of the State in the field of disability in the state of Assam, an effort has been made to find out various kinds of schemes that has been initiated by government of Assam so far.

4.5.1 The Schemes under the Government of Assam for Disabled People:

- A. Scholarship Stipend: The Government of Assam initiated two scholarship schemes in the year 2014-2015 with the objective to provide financial assistance to the disabled students, one at the post-matric level and another for the students pursuing technical and medical education.
- B. Rehabilitation Grant: The Scheme for one time Rehabilitation Grant of Rs10,000/ was started in the year 2017-2018 for the age group of 18 years to 50 years.
- C. Sahari: Project 'Sahari' was initiated in the year 2018-2019 to distribute aids and appliances free of cost to the needy beneficiaries.
- D. Other concessions/ Facilities: 5 percent reservation in the allotment of fair price shops and 3 percent beneficiaries under IRDP (Integrated Rural Development Programme) scheme are provided to the disabled persons.
- E. DeenDayalDivangya Pension from 2019 onwards 1000/ per month. Earlier, one time Financial Assistance of Rs 5000/ was provided on the eve of World Disability Day 2017 under DeenDayalDivangya Scheme. According to the data available in the directorate of Social Welfare department, Government of Assam 1,30,411 were benefited by the scheme. It needs to be mentioned here that Deendayal Divyanga Scheme was initiated by the Central Government in the year 2017 to provide one time financial grant to the persons with disability all over the country. However, out of 3.65.078 disabled people only 1,30,411 got the financial assistance.
- F. Un-employment allowance to Persons with Disability was initiated by the state government of Assam in the year 2018-2019.
- G. Allowance to employee with disabilities and child care allowance to women employees with disabilities was started in the year 2017.

From the above-mentioned schemes, two schemes viz. Scheme for Rehabilitation Grant and Scheme for scholarship to the students pursuing technical and medical education are selected for empirical investigation. As rehabilitation model is the one of the important models of the Government to address the issue of disability,

therefore Scheme for Rehabilitation Grant was selected. Under this scheme one time grant of Rs 10,000/- (Rupees Ten Thousand) is provided to the disabled persons. On the other hand, within the disabled people those who are pursuing medical and technical education can be considered as the most empowered category, therefore their opinion on government's schemes is also important to know the role of the State institutions in addressing the issue of disability. Under the scheme, the students with disability pursuing technical and medical education are provided Rs 35000/- (Thirty-Five Thousand)per annum.

4.5.2 Profile of the Scheme beneficiaries of Rehabilitation Grant:

The data available in the Office of the District Social Welfare, Kamrup Metro reveals that in the year 2017-2018, nine disability certificate holders are the recipient of rehabilitation grant of Rs 10,000/-.Again in 2018-2019, 10 disability certificate holders from Kamrup (M) District received the rehabilitation grant of Rs 10,000. Hence, 9 (nine) beneficiaries of 2017-2018 and 10 beneficiaries from 2018-2019 were interviewed by using a semi-structured schedule.

Table 4.2: Type and percentage of disability of the beneficiaries of Rehabilitation Grant for the session 2017-2018 in Kamrup (M) District:

Types of Disability	Number	Percentage of Disability	Age	Sex*	Educational Qualification
Multiple Disabilities	1	75	24	I	VII
Mental Illness	2	50	23	I	X
		65	26	I	X
Hearing Impaired	1	100	36	I	XII
Locomotor	5	40	35	I	X
		45	45	I	GRADUATE
		50	40	I	XII
		40	42	I	GRADUATE
		40	37	I	X

(Source : Field Survey)

*sex: I=male, II=female

The above table reflects the types of disability, percentage, age and educational qualification of the scheme beneficiaries. In the session 2017-2018, one beneficiary from multiple disabilities category, two from the category of mental illness, one hearing impaired category and five beneficiaries from locomotor disabilities are the recipients of rehabilitation grant. As regards the percentage of disability, all the beneficiaries are benchmarked disabled and only the beneficiary from the hearing-impaired category has 100 percent disability. The percentages of disability of two beneficiaries having mental illness are 50 percent and 65 percent respectively. The only one beneficiary having multiple disabilities is suffering from cerebral palsy having 75 percent of disability. The range of percentage of disability of the locomotor beneficiaries is from 40 percent to 50 percent. As regards the age group of the beneficiaries, three beneficiaries are from the age group below thirty, three beneficiaries are from the age group of thirty years to forty years and three are from the age group above 40 years. It needs to be mentioned here that in 2017-2018, no female candidate has received rehabilitation grant. Field study also reveals that the only one beneficiary from the multiple disability category studied

up to class VII, the two beneficiaries from the mental illness category studied up to class X. The beneficiary representing hearing impaired category has the educational qualification up to class X. It needs to be mentioned here that in 2017-2018 within the beneficiaries from the locomotor disability have the highest educational qualification i.e., graduate.

Table 4.3: Annual Family Income of the beneficiaries of Rehabilitation Grant in Kamrup(M) District for 2017-2018:

Annual Income of the family	No of beneficiaries
Below 2,00,000	5
2,00,000 to 5,00,000	3
5,00,000 and above	1

(Source: Field Survey)

The above table reflects the annual income of the beneficiaries' family. The field investigation reveals that annual family income of five beneficiaries is below 2,00,000, whereas three beneficiaries are from the category of income group 2,00,000 to 5,00,000 and one beneficiary is from the income group above 5,00,000.

Table 4.4 Type and percentage of disability of the beneficiaries of Rehabilitation Grant for the session 2018-2019 in Kamrup (M) District:

Types of Disability	Number	Percentage of Disability	Age	Sex**	Educational Qualification
Multiple Disabilities	1	60	20	I	VII
Mental Illness	2	80	23	I	X
		75	26	I	X
Hearing Impaired	2	100	45	II	XII
		100	34	I	X
Locomotor	3	60	25	I	Graduate
		70	30	I	Graduate
		60	25	II	XII
Visual Impairment/Blindness	2	75	26	I	Graduate
		100	46	I	XII

(Source : Field Survey)

**Sex: I=male, II= female

The above table portrays the types of disability, percentage, age and educational qualification of the scheme beneficiaries for the session 2018-2019. In Kamrup (M) district, ten (10) disabled persons received rehabilitation grant of Rs 10,000 for the session 2018-2019. As regards the types of disability one beneficiary is from the category of multiple disability, two from the mentally ill persons, two from hearing impaired category, three from locomotor disables and two from visually impaired category. It needs to be mentioned here that in 2017-2018 no visually impaired persons received rehabilitation grant. Field study reveals that in 2018-2019, all the beneficiaries having more than sixty percent of disability among which three beneficiaries are having hundred percent of disabilities. Among them two beneficiaries are from the hearing-impaired category and one belongs to the category of visual impairment. As regard the age group of the beneficiaries, highest number of beneficiaries is from the age group below thirty years (six beneficiaries), whereas two beneficiaries are from the age group of 30-40 years and two beneficiaries are from above forty years of age. It needs to

bementioned here that in 2018-2019, two female beneficiaries received the Rehabilitation Grant, one from hearing impaired category and the other belongs to locomotor disabled. Out of ten beneficiaries in the session 2018-2019, three were graduate, three studied up class XII, three were class X passed and one beneficiary studied up to class VII.

Table 4.5 Annual Family Income of the beneficiaries of Rehabilitation Grant in Kamrup(M) District for 2018-2019:

Annual Income of the family	No of beneficiaries
Below 2,00,000	6
2,00,000 to 5,00,000	4
5,00,000 and above	NIL

(Source: Field Survey)

The above table reveals that annual family income of six beneficiaries is below 2,00,000 and four beneficiaries are from the category of income group 2,00,000 to 5,00,000. In 2018-2019 no beneficiary is found from the income group above 5,00,000.

Again, the data available in the Office of the District Social Welfare, Jorhat District reveals that in the year 2017-2018, thirteen disability certificate holders are the recipient of rehabilitation grant of Rs 10,000/- and in 2018-2019, 10 disability certificate holders Jorhat District received the rehabilitation grant of Rs 10,000. Hence, 13 beneficiaries of 2017-2018 and 10 beneficiaries from 2018-2019 were also interviewed by using a semi-structured schedule.

Table 4.6: Type and percentage of disability of the beneficiaries of Rehabilitation Grant for the session 2017-2018 in Jorhat District:

Types of Disability	Number	Percentage of Disability	Age	Sex***	Educational Qualification
Multiple Disabilities	5	50	20	II	VII
		50	22	I	VII
		70	20	I	VII
		70	21	II	VII
		70	23	I	VII
Mental Illness	2	60	23	I	X
		75	26	I	X
Hearing impaired	1	100	25	II	XII
Locomotor	3	60	25	I	Graduate
		70	30	I	Graduate
		60	40	I	XII
Visual Impairment/Blindness	2	75	37	I	XII
		100	46	II	XII

(Source : Field Survey)

***Sex: I=male, II= female

The above table portrays the profile of the beneficiaries who received Rehabilitation Grant in Jorhat District for the session 2017-2018. Out of thirteen beneficiaries, five persons are having multiple disabilities, two persons are mentally ill, one person belongs to hearing impaired category, two persons are locomotor disabled and two disabled persons are from visually impaired category. As regards the percentage of disability, two disabled persons representing hearing impaired category and visual impairment have hundred percent of disability. The two beneficiaries having seventy five percent of disability are from the category of visual impairment and mental illness. Three beneficiaries from multiple disabilities and one locomotor disabled have seventy percent of disability. Again, two locomotor disables and one mentally ill person have sixty percent disability and two beneficiaries from multiple disability category

have fifty percent of disability. Field investigation also reveals that in Jorhat District in 2017-2018 maximum numbers of beneficiaries i.e., nine out of thirteen beneficiaries are from the age group below thirty years. Two beneficiaries are from the age group from thirty years to forty years and two beneficiaries are from the age group from forty years to fifty years. As regards the sex, four beneficiaries are female and nine beneficiaries are male. Field survey also reveals that in the session 2017-2018 two beneficiaries are graduate, four beneficiaries studied up to class XII, two studied up to class X and five beneficiaries studied up to class VII.

Table 4.7 Annual Family Income of the beneficiaries of Rehabilitation Grant in Jorhat District for 2017-2018:

Annual Income of the family	No of beneficiaries
Below 2,00,000	6
2,00,000 to 5,00,000	5
5,00,000 and above	2

(Source: Field Survey)

The above table shows the annual family income of the beneficiaries of Jorhat District for the session 2017-2018. Six beneficiaries were found from the income group below 2,00,000 whereas five beneficiaries were from the income group 2,00,000 to 5,00,000 and two beneficiaries were from 5,00,000 and above.

Table 4.8: Type and percentage of disability of the beneficiaries of Rehabilitation Grant for the session 2018-2019 in Jorhat District:

Types of Disability	Number	Percentage of Disability	Age	Sex****	Educational Qualification
Multiple Disabilities	2	50	34	I	X
		50	41	II	X
Mental Illness	2	80	23	I	X
		75	26	I	X
Hearing Impaired	2	100	45	I	XII
		100	34	I	X
Locomotor	3	60	25	I	Graduate
		70	30	I	Graduate
		60	42	I	XII
Visual Impairment/ Blindness	1	100	47	I	VII

(Source : Field Survey)

****Sex: I=male, II= female

The above table portrays the types of disability, percentage, age and educational qualification of the scheme beneficiaries for the session 2018-2019. In Jorhat District, ten (10) disabled persons received rehabilitation grant of Rs 10,000 for the session 2018-2019. As regards the types of disability two beneficiaries are from the category of multiple disability, two from mental illness, two from hearing impaired category, three from locomotor disability and one belongs to visual impairment. Among them three beneficiaries belonged to the age group below thirty years, three come under the age group from thirty years to forty years and remaining four beneficiaries are from the age group forty years to fifty years. It needs to be mentioned here that only one female beneficiary was found in the session 2018-2019. As regards educational qualification of the beneficiaries, one beneficiary studied up to class VII, five beneficiaries studied up to class X, two were XII pass and remaining two were graduate.

Table 4.9 Annual Family Income of the beneficiaries of Rehabilitation Grant in Jorhat District for 2018-2019:

Annual income of the family	No of beneficiaries
Below 2,00,000	6
2,00,000 to 5,00,000	4
5,00,000 and above	NIL

(Source : Field Survey)

The above table reflects that in 2018-2019 the annual family income of six beneficiaries of Jorhat District were found from the income group below 2,00,000 whereas remaining five beneficiaries come under the income group of 2,00,000 to 5,00,000. In the session 2018-2019, no beneficiary was found whose annual family income is above 5,00,000.

4.5.3 Responses of the Scheme Beneficiaries of Rehabilitation Grant:

A question was asked to the respondents regarding the source from where they have obtained the information about the scheme. The following table represents the response of the beneficiaries regarding the information about the scheme in Kamrup (Metro) district.

Table 4.10 Information regarding Rehabilitation Scheme in Kamrup (M) District:

Response	2017-2018 No of beneficiaries and percentage	2018-2019 No of beneficiaries and percentage
Social Welfare office	5 (55.6)	6 (60)
Advertisement in the news paper/ TV	2 (22.2)	2 (20)
Local NGOs	2 (22.2)	1 (10)
Health camp	NIL	1 (10)

(Source: Field Survey)

In Kamrup (Metro) District, five (55.6 percent) beneficiaries of the session 2017-2018 and six (60 percent) beneficiaries of 2018-2019 responded that they have got the information about the rehabilitation scheme during their visit to the District Social Welfare Office. However, two (22.2 percent) respondents of the session 2017-2018 and two (20 percent) respondents of 2018-2019 have informed that they were aware about the scheme from advertisement in the newspaper. Again, two (22.2 percent) respondents of the session 2017-2018 and one (ten percent) respondent of 2018-2019 have said that some of the social workers of local NGO provided the information about the scheme and help them in applying for the same. Besides, one (10 percent) respondent of 2018-2019 session has said that he obtained the information in the health camp jointly organized by the District Social Welfare Department and Joint director of the Health Services for issuing disability certificate.

Table 4.11 Information Regarding Rehabilitation Scheme in Jorhat District:

Response	2017-2018 No of beneficiaries and percentage	2018-2019 No of beneficiaries and percentage
Social Welfare office	5 (38.5)	1 (10)
Advertisement in the newspaper/ TV	1 (7.7)	NIL
Local NGOs	4 (30.8)	5 (50)
Health camp	3 (23.07)	4 (40)

(Source: Field Survey)

The above table shows that in Jorhat District five respondents (38.5 percent) of 2017-2018 and one respondent (10 percent) of 2018-2019 informed that they have collected the information about the scheme from the District Social Welfare Department. However, one respondent (7.7 percent) of 2017-2018 has referred to the newspaper advertisement about the scheme, which was published by the Directorate of Social Welfare, Government of Assam. Nine respondents, four (30.8 percent) from the session 2017-2018 and five (50 percent) from the session 2018-2019 has pointed out the

role of Prerona (a non-governmental organization working in the field of disability) in getting the scheme benefits. Again, according to the three (23.07 percent) beneficiaries of 2017-2018 and four beneficiaries (40 percent) of 2018-2019, they have got the information about the scheme when they participated health camp jointly organized by the Department of Social Welfare and Joint Director of Health Services, Jorhat District.

Another question was whether the beneficiaries have faced any problem in the process of applying for the Rehabilitation Grant. The responses of the beneficiaries are given below in tabular form.

Table 4.12: Problems relating to the application of Rehabilitation Grant:

District	Session			
	2017-2018		2018-2019	
	Yes	No	Yes	No
Kamrup (M)	6 (66.7)	3(33.3)	6 (60)	4(40)
Jorhat	9(69.3)	4(13.7)	5 (50)	5 (50)

(Source: Field Survey)

The above table reflects the responses of the beneficiaries/family members of the beneficiaries relating to the problems that they have faced during the process applying for rehabilitation grant. In 2017-2018, six beneficiaries (66.7 percent) from Kamrup (M) District and nine beneficiaries (69.3 percent) from Jorhat District informed that they faced lots of problems in the process getting grant under rehabilitation scheme. Again, six beneficiaries (60 percent) from Kamrup(M) District and five beneficiaries (50 percent) from Jorhat District in the 2018-2019 also mentioned about the problems that they faced in getting the benefits of rehabilitation grant. The respondents pointed out the problems at the time of collection and submission of application form. Some of the respondents were not even happy with the physical verification of the beneficiaries done by the officials of Social Welfare Department. According to them, as there are certain issues associated with the mobility of a disabled person, there is no requirement

of physical verification after having a disability certificate issued by a concerned authority. However, those who have replied the question in a positive manner in the sense that they are not facing any problem while applying for the scheme mentioned about the role of NGOs (Shishu Sarathi, Swabalambi in Kamrup (M) District and Prerona in Jorhat District) in the whole process of getting the rehabilitation grant.

At the time of interview, respondents belonging to different categories of disability expressed their viewpoints and life experiences in different ways regarding the problems and challenges they confronted at different junctures of their life. It may be mentioned that in case of mentally retarded and cerebral palsy person, parents, family members and caretakers were also interviewed to explore the ground realities. The major issues raised by the respondents are presented in the following matrix displaysⁱ given below under five broad themes.

Matrix Display I: Ambiguities of Disability Certificate

Theme	Response
Ambiguities of Disability Certificate	<p>A 35 years old respondent belonging to the locomotor disability category informed that he applied for the disability certificate only at the age of 21 years once he was being suggested by a doctor to do the same. He also informed that initially he applied in the Mahendra Mohan Choudhury Hospital for certificate and he had to wait for almost two months for the medical board. After having medical check-up he had to move to the district social welfare office several time to get the disability identity card and pass book. It is come to know from the interview that initially the disability identity card issued by the district social welfare office was purely temporary and valid only up to three years. Hence, he has to go to district social welfare office in every three years for the renewal of the same. However, he also informed that a few years back probably in 2012 or 2013, he managed to get the permanent disability certificate from the joint director of health. Therefore, he expressed his dissatisfaction in the whole process of issuance of disability certificate by the government and also informed that rehabilitation grant is the only benefit that he has received till now.</p> <p>Another respondent also belonged to locomotor disability category informed that she managed to get the disability certificate in a health camp held at the</p>

	<p>office of District Social Welfare, Beltola a few years back. She informed that several times she used to show the disability certificate for travel concessions in railway reservation counters. However, the railway official was reluctant to provide railway tickets at concession rate as the railway department has its own format of disability certificate for travel concession.</p> <p>Again another locomotor disabled informed that initially he got the disability certificate and Identity card ten years back under the initiatives of Regional Rehabilitation Centre located at Mahendra Mohan Choudhury Hospital, Panbazer.</p> <p>The parents of a cerebral palsy person almost 24 years of age informed that shishusarathi, anngo working in the field of early intervention and multiple disability sector made the necessary arrangement for getting the disability certificate.</p> <p>The parents of a deaf and dumb person who studied at Deaf and Dumb school Kahilipara informed that they received the disability certificate in health camp organized at the school.</p> <p>Family members of a mentally ill person informed that Ashadeep- A Mental Health Society has helped them out in getting disability certificate.</p> <p>Another three respondents from the Kamrup (M) District informed that Swabalami (anngo for community based rehabilitation) helped them in getting disability certificate.</p> <p>Seven respondents from the session 2017-2018 and three respondents from the session 2018-2019 of Jorhat district mentioned that Prerona help them in the process of getting disability certificate.</p> <p>It needs to be mentioned here that no one of the respondents has the Unique Identity card for persons with disabilities.</p>
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(Source: Field Survey)

Matrix Display II: Support System

Theme	Response
Support System	<p>As regards support system, the persons belonging to locomotor disability informed that their family members are the ultimate source of support in their life. Besides, they also acknowledge friends and others who often extend their helping hand to them in day to day life in general and transport and communication in particular. Out of five locomotor disabled beneficiaries from Kamrup (M) District of 2017-2018, three got wheel chair from the Social Welfare Department under the Scheme called Sahari. However, another two have applied for the same and not received yet. Again, three locomotor disables from 2018-2019 have received wheel chair. In Jorhat District under the initiative of Prerana wheel chairs have been distributed to all the beneficiaries under locomotor disability category.</p> <p>The parents and family members other than locomotor disabled informed that although they are the only support system for disables like cerebral palsy, mentally ill and so on. However, they expressed their sorrow and deep sense of fear psychosis regarding the future of those persons. Regarding the rehabilitation grant they are not much optimistic.</p>

(Source: Field Survey)

Matrix Display III: Awareness about Disability Rights

Theme	Response
Awareness	<p>As regards awareness about disability rights and entitlements, out of nine respondents of Kamrup (M) district four replied that they were aware of the PWD Act 1995. Among these four respondents two beneficiaries know about the RPWD Act 2016. It needs to be mentioned here that the two respondents who knew</p>

	<p>about RPWD Act were graduate and belonged to the locomotor disability category. However, most of the respondents of 2018-2019 from Kamrup (M) District were aware of the PWD Act 1995 and two of them mentioned that they are very much optimistic with the coming of new the Act i.e. RPWD Act 2016 that the Act will really fulfill their needs and aspirations. Again, in Jorhat District from both the sessions (2017-2018 and 2018-2019), only two respondents were aware about both the acts viz., the PWD Act 1995 and RPWD Act 2016. When a question was asked whether they have ever attended any seminar, workshop, awareness programme organized by government or non-government organization, answers of all the respondents were negative. On the other hand, some of the respondents informed that they are aware of different schemes of Assam Government like DeenDayalDivaynga Scheme, Rehabilitation Grant, Sahari, scholarship scheme and so on.</p>
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(Source: Field Survey)

Matrix Display IV: Views on Environment

Theme	Response
Environment	<p>The persons with disability as well as the family members expressed their dissatisfaction, sadness and depression on the issues pertinent to the environmental barriers that they confronted in everyday life. The locomotor disables were highly dissatisfied for the problematic infrastructure of the public buildings, day to day transport and communication system apart from the social and psychological barriers. They shared their life experiences, the way they are being excluded in the normal life.</p>

(Source: Field Survey)

Matrix Display V: Livelihood

Theme	Response
Livelihood	As regards livelihood, out of nine beneficiaries from Kamrup (M) District for the session 2017-2018 two are fully employed and three are partially employed and the rest are totally dependent on parents and other family members. One female locomotor disable has DTP centre where she has been working for last ten years. Another locomotor disable has a small chemist shop. The deaf person is associated with Shishu Sarothi on part time basis as sign language interpreter. The rest of one belonging to locomotor disability works as assistant in boutique and another has a paan shop. Among the respondents from 2018-2019 session, only two respondents are partially employed. One respondent works as a helper in the bus service of Ashadeep Day Care Centre and the other works as an assistant in a tailoring shop. As regards the livelihood of the respondents of Jorhat District, except one respondent from the session 2017-2018 who works as an assistant in Prerona, all are dependent on their respective families.

(Source: Field Survey)

4.5.4 Profile of the scheme beneficiaries of Scholarship under medical and technical education category:

For the student beneficiaries who received scholarship under medical and technical education category 24 number of beneficiaries in 2017-2018 and 20 respondents in 2018-2019 were interviewed from Indian Institute of Technology, Guwahati (IITG) and Jorhat Engineering College(JEC). In 2017-2018, twenty students received the scholarship and in 2018-2019 fifteen students received the same. Likewise, in JEC four students were the recipient of the scholarship in the session 2017-2018

and in the session 2018-2019, five students got the scholarship. It is come to know from the interview that all of the beneficiaries were enrolled under disability category. Again, it is noteworthy to mention here that no female candidate was found during the time of interview and as the beneficiaries are studying technical education, only two types of disabilities viz., locomotor disability and Hearing Impaired were found among them.

The types of disability along with disability percentage are shown below separately for the session 2017-2018 and 2018-2019 in tabular forms:

Table 4.13: Type and percentage of Disability of beneficiaries of Scholarship Scheme in 2017-2018:

IITG					JEC				
Types of Disability	Number	Percentage			Types of Disability	Number	Percentage		
		40-50%	51-60%	61-70%			40-50%	51-60%	61-70%
Locomotor	18	10	4	4	Locomotor	3	3	0	0
Hearing Impaired	2	0	0	0	Hearing Impaired	1	0	1	0

(Source: Field Survey)

The above table shows that only two categories of disability viz. locomotor and hearing impaired were found in the session 2017-2018. As regards the disability percentage of the locomotor disabled students studying in IITG, ten are having 40-50 percent of disability, four students have 51-60 percent of disability and remaining four comes under 61-70 percent of disability. Likewise, in JEC the three locomotor disabled students have 40 -50 percent of disability. The two-hearing impaired disabled students of IITG have 40-50 percent of disability and the only one hearing impaired student of JEC has 51-60 percent of disability.

Table 4.14: Type and percentage of Disability of beneficiaries of Scholarship Scheme in 2018-2019:

IITG					JEC				
Types of Disability	Number	Percentage			Types of Disability	Number	Percentage		
		40-50%	51-60%	61-70%			40-50%	51-60%	61-70%
Locomotor	15	10	3	2	Locomotor	5	4	1	0
Hearing Impaired	0	0	0	0	Hearing Impaired	0	0	0	0

(Source: Field Survey)

The above table reflects the types and percentage of disability of the student beneficiaries for the session 2018-2019. In this session only the beneficiaries from the locomotor disability categories were found. Out of the fifteen locomotor disabled students of IITG, ten students have 40-50 percent of disability, three students have 51-60 percent of disability and remaining two students come under 61-70 percent of disability.

Table 4.15: Annual Family Income of beneficiaries of Scholarship Scheme:

Family income of the respondents	IITG		JEC	
	2017-2018	2018-2019	2017-2018	2018-2019
Below 5,00,000	8 (40%)	5 (33.3%)	1 (25%)	1 (20%)
Above 5,00,000	12 (60 %)	10 (66.7%)	3 (75%)	4 (80%)

(Source: Field Survey)

The above table shows the annual income of the families of the student beneficiaries pursuing technical education in IITG and JEC. In 2017-2018, eight beneficiaries (40%) of IITG and one beneficiary (25%) of JEC belonged to the income group below 5, 00,000 and in 2018-2019 five beneficiaries (33.3%) of IITG and one

beneficiary of JEC (20%) come under the same income group. Field investigation also reveals that the number of students belonged to the family income group of Rs above 5,00,000 is higher than the students having family income group below 5,00,000 i.e., twelve (60%) beneficiaries in 2017-2018 and ten beneficiaries (66.7%) in 2018-2019 from IITG and three beneficiaries (75%) in 2017-2018 and four beneficiaries (80%) in 2018-2019 from JEC.

As regards other stipend apart from the fellowship provided by the Social Welfare Department, Government of Assam, twelve students from IITG have informed that they have received central government fellowship for the disabled students studying in the best institutions of the country. However, seven students of the same institution said that they have applied for the same fellowship and hopefully will receive in the coming session. On the other hand, the beneficiaries from the JEC have informed that they are not aware of any other fellowship for disabled students.

4.5.5: Responses of the scheme beneficiaries of Scholarship under medical and technical education category:

A question was asked to make an overview of the existing facilities like ramp, toilet, transportation, rehabilitation material, regular medical checkup etc. of the institutions. The beneficiaries of both the institutes replied that in they have ramp facilities in their institutes for disabled students. As regard the toilet facilities, the respondents of IITG have mentioned that disabled friendly toilets are available in their institute. However, the students of JEC said that the disabled friendly toilets of their college are still not in functional mode, these are under constructions only. Again, the students of IITG have informed that they are also availing the transport facilities as well as rehabilitation materials e.g., wheel chair. But the students of JEC have mentioned that they are not getting such type of facilities in their institute. They also pointed out that no regular medical checkup is done in the institute.

A question was asked to the respondents to know the level of awareness about different legislations and provisions related to disability. It is pertinent to mention here that all the respondents of both the institute knew about PWD Act 1995 as well as

RPWD Act 2016. They further informed that sometimes they participate in deliberations and discussions on the issue of disability organized by different state or non-state organizations.

4.6 Conclusion:

The above discussion reveals that in the recent years number of initiatives have been made on the part of the government for mainstreaming disabled persons with the greater society and accordingly the role of the State is naturally expanding while formulating new policies and executing those for reaching the unreached. Over the years, many changes have been taken place in the field of disability and several institutional arrangements have been made for ensuring rights and reasonable accommodation for persons with disability. Those are of course welcome development. However, many of the government policies and initiatives are at times cosmetic developments that yet to address the real issues of disability. As for example, in the recent time the Government is calling online application for providing unique identity card for persons with disability to avail the government benefits. Needless to say, this kind of initiatives on the part of government is a piecemeal approach towards addressing the issue of disability. It is because for a person with disability may be a blind or low vision person or for mentally ill person or persons suffering from multiple disabilities, it is almost impossible for them to handle the online applications. Besides, persons with disability residing in rural remote areas, it is serious challenge to educate and make them aware about their rights and government schemes beneficial for them. Apart from rural urban disparity, gender is also a serious issue of concern pertinent to disability. The empirical investigation of the present study reveals that the number of female beneficiaries is very less compared to its male counterpart and more particularly in case of technical educational institutions. Moreover, there are many other complex issues that need to be taken into considerations while addressing the issue of disability. But, in most of the cases Government approach is a blanket approach that fails to touch the untouched and often ignores the deeper complexities of the problem.

While looking at the role of the State in disability, the present study focuses on the functioning of the institutions pertinent to disability through which the State machinery operates and performs its role as a rational political institution of a given society. However, it has been observed that there is a lack of proper coordination among various government departments for achieving a particular goal as reflected in the disability legislations. For example, for barrier free environment in public places requires a proper coordination between Public Works Department and Transport Department of the government. But, till now, the government has not taken any initiative to maintain a coordination between these departments for orienting them in making a barrier free environment. Hence, it can be said that although the State is playing a role in the field of disability its role has not been found to be up to the satisfaction due to the lack of coordination or overlapping of responsibilities at the functional level.

ⁱ Matrix display is a thematic representation of qualitative data. In matrices table of rows and columns are used to portray a general situation, detailed chronologies, the actions of people in different roles, the interplay of variables, and so on. See for details Miles., B. Mathew, A. Micheal Huberman and Johny Saldana, *Qualitative Data Analysis: A Methods Sourcebook*, Sage 1994, London.

CHAPTER V

FUNCTIONING OF THE NON-GOVERNMENTAL ORGANIZATIONS IN DISABILITY SECTOR IN ASSAM: AN EMPIRICAL INVESTIGATION

5.1 Introduction:

The present time is marked by the rearrangement of power structure and transformation of politics of a given society. The contemporary moment in history witnesses that the nature of the state power has totally turned upside down over the years. A post-modernist like Micheal Foucault describes the State as nothing more than the mobile effect of a regime of multiple governmentality (Tremain, 2005, Pp. 1-24). As mentioned in the Chapter III, governmentality refers to the technology of power that generates knowledge about population and in a way make them governable. In that sense, Foucault emphasizes on the governmentalization of the state. With the acceleration of the process of globalization it has been argued that the role of the state is diminishing, and the private and non-state actors are becoming more and more significant. However, many post-modern critiques argued that –

It is not a diminishment or reduction of state sovereignty and planning capacities but a displacement from formal to informal techniques of government and the appearance of new actors that is the non-governmental organizations in the scene of government (Lemke,2002. Pp.1-24))

This indicates the fundamental transformation in statehood and a new relationship has developed between state and the non-state actors. Hence, a gradual shift has been noticed for the social responsibilities such as illness, unemployment, poverty etc. from state to non-governmental organizations (NGOs hereinafter).

In simple sense, NGOs refer to the non-profit, heterogenous entities of a society which are primarily independent of state and international organizations and usually funded by donations and may rely heavily on volunteers for their operations (however, the NGOs may receive government support for the fulfillment of their projects).It

comprises of different set of organizations such as “private voluntary organizations,” “civil society organizations,” and “non-profit organization” (McGann & Johnstone, 2006), starting from watchdog activist groups and aid agencies to development and policy organizations. Generally, NGOs pursue a public interest agenda, rather than commercial interests (Hall-Jones, 2006) and play important role in developing society, improving communities, and promoting citizen participation. Their activities may include, although not limited to, environmental, social, advocacy and human rights work. Hence, by fulfilling the gap of the government services and protection for citizens NGOs can play a substantial role in the transformation of society.

World Bank defines NGOs as “private organizations that pursue activities to relieve suffering, promote the interests of the poor, protect the environment, provide basic social services or undertake community development”.

The United Nations Organization, Department of Public Information (DPI) defines the NGO as “a not-for profit, voluntary citizen's group that is organized on a local, national or international level to address issues in support of the public good.”

Again, Green and Mathias (1997) defined NGOs as “Organizations that are formally constituted, with a primarily non-profit-seeking objective of a group or community wider than the direct membership of the organization and with a decision-making authority independent of government. They may achieve their aims in a variety of ways ranging from direct service provision through to the support of other NGOs”.

Korten (1990) classifies NGO into wide variety of organizations. They include: 1) Voluntary organizations that pursue a social mission driven by a commitment to shared values; 2) Public Service Contractors that function as market oriented non-profit business serving public purposes; 3) People's organizations that represent their members' interest, have members accountable leadership, and are substantially self –reliant and 4) Governmental-nongovernmental organizations that are creations of government and serve as instruments of government policy.

It needs to be mentioned here that as NGOs are devoted to the growth, welfare and development of the people from the marginalized and underprivileged communities, they play a proactive role in the field of disability too. Generally, NGOs try to address both the models of disability viz medical model and social model. While emphasizing

the role of medical model, NGOs initiate certain rehabilitative measures for the disabled people and interventions for human rights advocacy, inclusive education, empowerment, reasonable accommodation etc. are included under social model of disability. However, rehabilitation is a holistic and integrated approach which not only includes the medical intervention, but also the efforts to make the disabled people empowered in their own way. Although, institutional based rehabilitation is the common approach for the NGOs associated with disability, Community Based Rehabilitation (CBR hereinafter) has also become a popular method of disability rehabilitation for some of the NGOs after its introduction by World Health Organization (WHO) following the Declaration of Alma Ata in 1978. CBR refers to the community-based development strategy aiming at the enrichment of the quality of lives of the disabled persons and their families within their community. It is noteworthy to mention here that combined efforts of people with disabilities, their families and communities, and relevant government and non-government organizations are essential for the proper implementation of CBR. It involves overall development of disabled persons including health, education, vocational training, social and other services etc. In India systematic efforts by the NGOs in the field of disability rehabilitation was started only after the declaration of International Year of Disabled Persons (IYDP) in 1981. It needs to be mentioned here that NGOs that have been working in the field of disability in India include imparting education, vocational training and both institutional and community-based rehabilitation. In Assam too, a number of NGOs are working in disability sector particularly in the field of children with disability, intellectual disability, education for disables, rehabilitation of mental illness, community-based rehabilitation and so on. Of course, emergence of NGOs in disability sector in Assam is a recent phenomenon. From 1980s onwards very few numbers of NGOs have been seen working in the areas mentioned above. A detailed profile of the NGOs working in the state of Assam has already mentioned in the Chapter III.

In the present chapter, for understanding the role of NGOs in disability sector, four NGOs viz., Shishu Sarothi, Ashadeep: A Mental Health Society, Swabalambi Prerona: Spastic Society were selected for empirical investigation based on purposive sampling method. The field study was conducted from June 2017 to June

2019. The reason for the selection of these four NGOs is that each NGO is engaged with different set of activities and assignments pertinent to disability. For instance, Shishu Sarathi deals with the issues associated with multiple disabilities, while Ashadeep is mainly concerned with mental disability. Similarly, Swabalambi is an NGO based on community-based rehabilitation. On the other hand, Prerona: The Spastic Society is an NGO located in Jorhat district of Assam acts as a District Disability Rehabilitation Centre (DDRC) of the Government of Assam along with its other responsibilities. Hence, it can be considered that these NGOs represent four different dimensions of activities associated with disability in the state of Assam.

5.2 Shishu Sarathi:

Shishu Sarathi offers different services to the children with multiple disabilities including early intervention as well as inclusive education. It conducts comprehensive training programmes for different groups of people including special educators, school teachers, parents of disabled children, human rights activists and so on. Certain sensitization programmes and awareness are also initiated by Shishu Sarathi to make people aware about different issues associated with disability and to uphold the rights of the persons with disabilities (mentioned in the Chapter III).

Services of Shishu Sarathi:

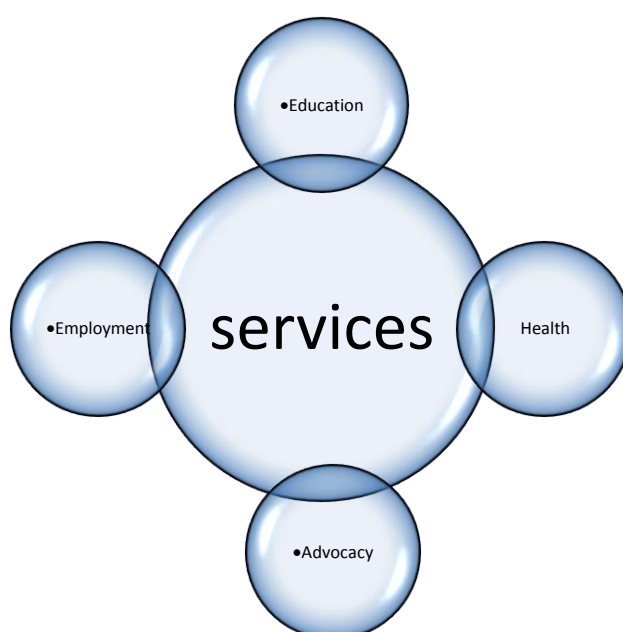


Table 5.1: Organizational structure and staff of Shishu Sarothi :

Unit	No of staffs
Centre for Inclusive and Vocational Education (CIVE)	7
Early Intervention Unit (EIU)	15
Information and Communication Technology Laboratory (ICT LAB)	6
Human Resource Development Division	6
Disability Law Unit	4
Disability Employment Initiative (DEI)	4
RAISE North East (Project)	8

(Source: Field Survey)

Shishu Sarothi has been involved with different Government and non-Government agencies for donations/grants, guidance, knowledge sharing, etc. the following table shows the list of partners associated with Shishu Sarothi:

Table 5.2 List of partners of Shishu Sarothi:

Sl no	Name of the partner
1	Department of Empowerment of Persons with Disability, Ministry of Social Justice and Empowerment, Government of India
2	Rehabilitation Council of India
3	Department of Social Welfare, Government of Assam
4	Azim Premji Philanthropic Initiatives
5	Light for the World, Christoffel Development Cooperation
6	Indus Towers: Putting India First
7	Johnson: A Family Company
8	Sense International India
9	NumaligarhRefinery Limited

Source: Field Survey

5.2.1 Activities of Shishu Sarothi during the session 2017-2018 (Source: Annual Report):

- During the session 2017-2018, thirty students were enrolled under inclusive curriculum of the organization. The curriculum was designed in such a manner that it can incorporate both disabled students and non-disabled students. Basis emphasis was given on ‘play way’ methodologies. It needs to be mentioned here that among these students, four students were mainstreamed during this year.
- During 2017-2018 a series of sensitization programmes were conducted under Sarva Shiksha Abhiyan for teachers and principals of nine schools. The basic objective of these sensitization programme was to promote inclusive education.
- One paper Craft Training for young adults with disabilities was organized to teach to make a range of products including paper bags, decorative envelopes, notebook covers. The products were also sold through various forums during the year in Guwahati.
- A two-day training programme was organized on the use the software ‘e-saadhya’ for the teachers/ special educators and therapist on the topic Applied Behaviour Analysis (ABA) in the ICT lab. It needs to be mentioned here that ‘e-saadhya’ is a software designed to provide a complete learning solution to students with intellectual disabilities and mild autism spectrum disorder (ASD).
- During 2017-2018 thirteen students were given skill development training. As regards preparation for HSLC and HS examinations four students were prepared for HSLC and four were prepared for HS examination.
- As mentioned in the Chapter III, Bharati Infratel scholarship programme is provided to the students with disabilities from the North Eastern region for pursuing higher education. It is come to know from the field investigation during June 2017 to 2019, out of one hundred seventeen applicants forty students were selected for scholarship.
- It needs to be mentioned here that Shishu Sarothi conducts different training programmes / certificate courses on disability studies affiliated to the Rehabilitation Council of India (RCI). In January 2018, a six months course on ‘Advanced Certificate Course in Inclusive Education (ACCIE)’ (Cross Disability) was introduced under Training/ Human Development Division

(HRD). The programme was mainly designed for subject teachers in SSA schools. In July 2018, 16 participants have successfully completed the course.

- Under Early Intervention Unit (EIU) 490 babies were assessed at CRC Guwahati during the period of field investigation out of which 263 were new cases. 5260 sessions were conducted between June 2017-June 2018 for the assessment of the children as well as counselling of the parents. Besides, different health and hygiene camps and workshops were organized for oral health and dental hygiene as well as other related issues.
- As regards the disability advocacy programme for the inclusion across the region of Shishu Sarothi advocacy campaigns viz, 'Include Vidya Campaign', 'Ring the Bell', I-inspire by *Pinkathon* were organized during 2017-2018. Besides, in collaboration with Netaji Subhas Open University and National Institute of Public Cooperation and Child Development (NIPCCD), a rehabilitation programme for thirty special educators were organized on the topic 'Understanding Learning Disability, Assessment, Diagnosis and Intervention' in June 2017. Again, for 10 RAISE Assam partners, a three-day Advocacy training on RPWD Act 2016, UNCRPD and RTE was held at Khanapara in August 2017.
- Fifteen numbers of different counselling sessions were conducted among parents as well as other stakeholders. The topics incorporated in the sessions were behaviour management, pre-academic skills, parents' involvements, importance of support groups etc.
- Under Communication Developmental Eclectic Approach to Language Learning (ComDEALL) approach of the organization early intervention provides to the children having communication problems, particularly those children with autism spectrum disorders. During the period of field investigation 24 children in two batches received individualized therapy.
- The Disability Law Unit of the organization through various awareness, sensitization, capacity building programmes could reach 730 participants during the session 2017-2018. For the greater interest of the communities, parents, teachers, Disabled Peoples' Organizations (DPO) and other stakeholders of Assam and other north eastern states, state levels seminars on the rights of the

persons with disabilities were organized. In 2017, Disability Law Unit of Shishu Sarothi translated the RPWD Act 2016 into Assamese.

5.2.2 Activities of Shishu Sarothi during the session 2018-2019 Source: Annual Report:

- In the Centre for Inclusive and Vocational Education (CIVE) twenty-eight new Children were enrolled in the year 2018-2019. Among them five students were mainstreamed and studying in regular schools. In the month of November 2018, yoga class was also introduced.
- In 2018-2019, seventy-five SSA schools from five states of North East India viz., Assam, Manipur, Meghalaya, Nagaland and Tripura were selected to complement the different components of inclusive education for children with disabilities in Samagra Siksha Abhiyan (SSA). Shishu Sarothi has collaborated with fifteen different NGOs from these states to fulfil the purpose. Besides, the organisation also initiated certain advocacy campaigns by organising Ring the Bell campaign and conducting the Zonal's Children Meet. It needs to be mentioned here that Ring the Bell campaign is a signature campaign, which was organised from 13th to 19th March 2019. The main objectives of the campaign were to create awareness among teachers to provide equal opportunities to the children with disabilities in the class room activities as well as sensitize the communities on the enrolment of children with disabilities in the regular schools.
- In October 2018, Shishu Sarothi launched a project on English Access Micro Scholarship Programme in association with the US Consulate. The basic purpose of the project was to provide knowledge on functional English to the students with and without disabilities within the age group of 13 to 20 years mainly from the economically weaker sections of the society. The project was started in two places, one in the Shishu Sarothi centre itself and another in association with the Hill Crest School, Shillong.

- Under Bharati Infratel Scholarship Programme, from one hundred ninety-six applicants, ninety-five students were selected for scholarship during the session 2018-2019.
- Two training programmes were organised for deaf-blindness in the session 2018-2019. One from 27th to 29th November, 2018, which was in North East Regional Training on Deaf-blindness and another was in the Assam State Medical and Paramedical Training on Deaf-blindness on 14th December, 2018.
- In the Early Intervention Services, total 4454 total sessions were conducted and 317 new children were enrolled during the session 2018-2019. Among them 65 neonates were referred from Neonatal Intensive Care Unit of the Paediatrics Dept of GMCH. During this session 209 high risk babies were assessed by EIU and subsequently counselling was provided to the families.
- Besides, weekly intervention services were also offered in some of the neighbouring districts of Assam and Meghalaya to the young children with disability in collaboration with a local NGO of the concerned district. Thirty-nine children from Kokrajhar, Chirang, Barpeta, Dhubri and Bongaigaon and eleven children from Meghalaya were benefited from the service.
- During the session 2018-2019, in collaboration with Voluntary Services Overseas (VSO), a study titled 'SDG Disability Tracker II' was conducted in the post conflict districts of Chirang and Kokrajhar, Assam to understand the situation and conditions of persons with disabilities. The study assessed mainly three dimensions of Sustainable Development Goalsⁱ (SDGs) viz, gender equity, clean water and sanitation and decent work and economic growth.
- In collaboration with State Election Commission, Assam sensitization programmes were organised on conduct of accessible election for 4000 officials and members of the public in Assam. The programme was done in two phases – five zones in October 2018 and eight zones in March 2019. Besides, various street plays were also organised in different locations for the cause of sensitisation.

5.2.3 Stories from Shishu Sarothi:

During the time of field investigation an effort was also made to know some of the success stories from the different stakeholders to explore the proper functioning of the organization. The following box represents some of the impact stories narrated by the different stakeholders including parents of the disabled children associated with Shishu Sarothi:

Box I: Success Stories of Shishu Sarothi

- One six years old girl diagnosed with autism spectrum disorder with continuous echolalia (repetition) was enrolled in EIU (supported by ComDEALL) in 2014 with lack of communication skill in accordance with her age. With continuous efforts and interventions of the concerned persons of the organization, the girl could communicate and answer some simple questions. The girl also developed the concept colour and Shishu Sarothi was in a position to mainstream her in the regular school in 2017.
- A six-month baby was taken to EIU of Shishu Sarothi by her parents with no head control and hypotonic muscle tone. The Unit was actively involved with the case for two years by providing her head control exercises, deep joint pressure, muscle strengthening and other appropriate exercises for improving her posture and positioning. After two years of continuous intervention, finally the girl was able to walk without any support and gradually she started to play with her peer groups too.
- One year old boy suffering from cerebral palsy with associated problem of poor vision and no speech was taken to the Early Intervention Outreach Programme at Goalpara (Supported by SESTA) by his mother. When the child brought to EIU of Shishu Sarothi, he could just sit up. However, after continuous intensive therapy and stimulation for six months, the child started walking and also seemed to enjoy the therapies.
- As a response to the legal action initiated on behalf of a PhD Scholar with Thalassaemia, applying for UGC Scholarship at Tezpur University, the first ever Disability Certificate was issued for the person with Thalassaemia in Assam (new disability recognized under the RPWD Act 2016)

- In response to petition of person with hearing impairment, Hon'ble Gauhati Court turned over the hitherto ineligibility of persons with hearing impairment to become Teachers /Assistant Teachers under the Teachers' Eligibility Test norms of Govt of Assam. The petitioner was then allowed to appear before the State Level Medical Board for verification of disability status.

(Source: Field Survey)

It needs to be mentioned here that Shishu Sarothi has been awarded at different point of time for rendering its service to the society. The box given below represents some of the awards achieved by Shishu Sarothi:

BoxII: Institutional Awards achieved of Shishu Sarothi:

- National Award for Best Institution (Additional) from the then President of India in 2004
- State Award for Best Community Service from the Chief Minister of Assam in 2007
- Founder Director, Mrs Mira Kagti was also conferred with the Rajiv Gandhi Manav Seva Award in the year 2010, conferred by the Ministry of Women and Child Development, Govt of India
- Award as the PoorvatraPradeshi Marwari Yuva Manch in the year 2013.
- XIVth AIWEFA – Nina Sibal Memorial Award 2016 for outstanding Work for People with Special Needs.

(Source: Field Survey)

5.3 Ashadeep: A Mental Health Society

Ashadeep: A Mental Health Society is an NGO working for the rehabilitation of the persons with mental illness. The activities of Ashadeep includes picking up the homeless persons with mental disorder, their treatment and rehabilitation, reintegration with their respective families, generating certain employment opportunities etc. It has also the service of Day care Rehabilitation for the individuals with intellectual disability and associated disorder.

Services of Ashadeep: A Mental Health Society



*Community Mental Health Programme was an outreach programme from 2012-2016.

Table 5.3: No of Staffs in Ashadeep:

Social worker	5
Psychologist	2
Psychiatrist	2
Psychiatric Nurse	1
Medical Doctor	1
Day care Teacher	9
Attendant	12
Health care staff	10
Field worker	7
Driver	3
Vocational worker	3

(Source: Field Survey)

Ashadeep has been involved with different Government and non-Government agencies for donations/grants, guidance, knowledge sharing, etc. the following table shows the list of some of the partners associated with Ashadeep:

Table 5.4 List of partners of Ashadeep:

Sl no	Name of the partner
1	Department of Social Welfare, Government of Assam
2	Department of Health, Government of Assam
3	The Hans Foundation, New Delhi
4	GiveIndia, Mumbai
5	Special Olympics Bharat (Assam Chapter)
6	PRERONA- IAS Officers Wives Association, Guwahati
7	Sitaram Jindal Foundation, New Delhi
8	MorigaonMohila Mehfil, Morigaon
9	Assam Donbosco University
10	Shamdasani Trust, Hongkong
11	The Banyan, Chennai

(Source: Field Survey)

5.3.1 Ashadeep Day Rehabilitation Centre:

Ashadeep Day Rehabilitation Centre has been trying to provide day care rehabilitative services to more than six hundred individuals with intellectual disabilities. During the of field investigation eighty-five students were enrolled in the centre. The students are provided training both in conventional and pre-vocational education, life skills, social and communication skills, extra-curricular activities like yoga, music, drama, art and craft session etc.

5.3.2: Rehabilitation Homes for Homeless:

As mentioned in the Chapter III, Ashadeep has the facility of two rehabilitation homes for homeless, abandoned mentally ill persons viz Navachetana Rehabilitation Home for homeless women with mental illness and Udayan Rehabilitation home for homeless men with mental illness. The basic objective of the residential rehabilitation service of Ashadeep is not only to provide rehabilitation services to the mentally ill persons until the process of reintegration with their families not completed. Hence, an

effort has been made in the process of field investigation to know the process how Ashadeep has been involving with the rehabilitation as well as reintegration process. After reintegration with the families, regular follow up is also done by the organization and the patients are also advised to visit its psychiatric outdoor clinic. The process of rehabilitative Intervention of Ashadeep is given below (Source: Annual Report of Ashadeep 2017-2018):

- Assessment and intervention for mental and physical health ailments
- Care and Rehabilitation
- Scientific tools are used to assess mental status, progress of treatment, disability level, functionality level etc.
- Re- introduction of life skills, pre-vocation and vocational training in a homely set up so that they can have a better experience during reintegration.

During the field investigation it is also observed that apart from providing psycho-social rehabilitation, the residents are also encouraged to engage in certain vocational activities which is named as **Positive Reinforcement Therapy**, where everyone gets incentive for their productive engagement as soon as their symptoms are controlled. The male residents generally engage in gardening, vegetable farming, cattle farming, poultry, piggery and duck farming and on the other hand the female residents are assigned the activities like household work, weaving, jute braiding, stitching door mates and carpets with recycled cloth. It needs to be mentioned here that during the rehabilitation process each and every resident has to follow a routine life where yoga therapy, music therapy, sports therapy etc. are given to them. Regular monitoring of health is also done along with psychological counseling. A total number of 906 homeless women and men have been admitted till March 2019 and among them 844 were reintegrated with their families across the country.

Table 5.5 Total no of persons admitted in the Rehabilitationhouses of Ashadeep in 2017-2018 and 2018-2019:

Facility	By Ashadeep		By Police		By NGOS		Readmission		Total Admission	
	2017-2018	2018-2019	2017-2018	2018-2019	2017-2018	2018-2019	2017-2018	2018-2019	2017-2018	2018-2019
Navachetana	2	1	16	15	17	18	13	4	48 (53.3%)	38 (53.5%)
Udayan	20	15	12	7	10	11	-----	-----	42 (46.7%)	33 (46.5%)
Total:									90	71

(Source: Field Survey)

The above table reflects the number of persons admitted to the rehabilitation houses of Ashadeep for the session 2017-2018 and 2018-2019. In both the session the number of women {48 (53.3%) in 2017-2018 and 38 (53.5%) in 2018-2019} is slightly higher than the men {42(46.7%) in 2017-2018 and 33 (46.5%) in 2018-2019}. It is also evident from the table that along with Ashadeep's own initiatives, police and other NGOs also take initiatives to bring the mentally ill persons to the rehabilitation houses. As regards readmission for rehabilitation, the number of male patients was nil in both the session.

Table:5.6 A Brief Summary of Reintegration of persons by Ashadeep in 2017-2018 and 2018-2019

Session	Navachetana			Udayan			Grand Total
	Assam	Other states	Total	Assam	Other States	Total	
2017-2018	27 (87.1%)	4 (12.9%)	31 (100%)	24 (57.1%)	18 (42.9%)	42 (100%)	73
2018-2019	36 (81.8%)	8 (18.2%)	44 (100%)	21 (63.6%)	12 (36.4%)	33 (100%)	77

(Source: Field Survey)

The above table shows the number of persons reintegrated with their families in the session 2017-2018 and 2018-2019. It is evident from the table that 73 persons were reintegrated during the session 2017-2018 and 77 persons were reintegrated in 2018-2019.

5.3.3 Home again: Independent Shared Housing in the community for residents of Navachetana and Udayan:

Although the ultimate objective of Ashadeep is to reintegrate the homeless residents of Navachetana and Udayan with their families, it was known from the field investigation that approximately ten percent of the residents cannot be reintegrated with their families. Hence, Ashadeep has arranged the facility of independent shared housing in the year 2017 for those residents who have completed at least one year in the rehabilitation homes and have reduced positive symptoms related to their illness. Now Ashadeep has the facility of 3 urban homes at Rehabari and Japorigog, Guwahati and 3 rural homes at P.L. Home Campus, Bamunigaon, Boko, Kamrup Rural, Assam. The urban homes are for female residents and rural homes are for male residents. Each home is having the capacity of five persons, where they live their lives like any other normal people of the society. However, the residents have to take regular medicine and other therapies. It was observed during the time of field investigation that in the home again of Bamunigaon, the residents are taking care of pet animals like dog, rabbit, different birds etc as a part of their **pet therapy**. During the time of field investigation, nine persons were residing in rural set up and ten were in urban set up and they were engaged in different activities for their livelihood. Six women from the urban shared home work in an NGO named AtmaNirbhar: Ek Challenge, engages in packaging tea and grocery items, one involves as a teacher in Ashadeep's Day Rehabilitation Centre, one works as a housemaid. Most of the male residents of the shared home are engaged in the piggery, poultry etc farm within their campus. However, one resident works as a handyman in Ashadeep's school bus, two have vegetable shops in Bamunigaon and one resident is running a mobile grocery shop.

5.3.4 Stories from Ashadeep:

To know more about the whole process of mental rehabilitation and care, informal interview was conducted with the director, office staffs, social workers, psychologist etc of the organization. They have shared different stories narrating the process of rehabilitation starting from the admission of the residents. Some of the stories narrated by them are given below:

- One patient was admitted to Ashadeep on 17th January 2017 by sister's from Missionaries of Charity (MOC hereinafter), Lankeshwar, Guwahati, Assam. After admission she was diagnosed as psychosis. However, within a month of her admission, remarkably certain changes were noticed by the staffs and doctors of the organisation regarding the recovery from her illness. Keeping this in mind, she was engaged as a kitchen attendant in the Ashadeep Transit care and she became complete functional after one year. As she could not locate her house, Ashadeep could not reintegrate her and she was shifted to urban shared house. Meanwhile, she was engaged in AtmaNirbhar: Ek Challenge for packaging of tea and other items, where she started earning Rs 2500/- per month. The administration of Ashadeep also helped her to open a bank account. One day while returning from her workplace, she got surprised when she suddenly met her daughter who stays nearby. After a week of their meeting, the daughter took her home after taking permission from the administration of Ashadeep. Although, the patient is now leading a normal life, she is taking regular medicines and follow up on monthly basis.
- Another story regarding the relapsing of the illness due to unavailability of medicines in some remote areas was narrated by one of the social workers met during the period of field investigation. It was informed by the social worker that one person was picked up from Guwahati Club area, Guwahati, Assam by the Ashadeep staff on 12th September 2017. The person was belonged to a remote area of Nagaland and after receiving treatment and care in Ashadeep for five months, he was reintegrated to his family. However, on 31st May, 2019, he

was readmitted in Udayan. It was known from the social worker that due to the unavailability of medicines in the locality of the person his symptoms of restlessness relapsed. The social worker also informed the story how he was readmitted in the organization. As the person felt that his earlier symptoms are going to relapse, he immediately came to Guwahati. However, he could not locate Ashadeep and took help from one bus conductor.

- One person residing in the home again from rural set up shared his experience in Ashadeep. Earlier, the person worked in a call centre located at Kolkata. However, due to some family issues and other problems, he was intoxicated and gradually he developed some unnatural behaviour. He informed that he was picked up by the police from the Guwahati Railway station and admitted him to Ashadeep. He was diagnosed with the symptoms of delusion, hallucination, irrelevant speech etc. After continuous intervention by the doctors and staffs of the organization for one year, he was in a position to go home. However, after reaching home he faced another type of problems. As his mother was a mentally retarded person, there was no acceptability of his mother in the family. Meanwhile, he was again shocked because of the demise of his mother. Therefore, he again came back to Ashadeep and requested to give him shelter. Although after reintegration Ashadeep does not have this provision, the organisation specially considered his request. Since then, he is staying in the home again set up and running a mobile grocery shop. He also informed that along with his regular medicine, he is taking care of three rabbits, two dogs and four birds as a part of pet therapy.

Box: III Ashadeep as a Resource Centre

Ashadeep as a resource centre

Ashadeep, as a service provider in the field of mental health initiates various training, advocacy, orientation, sensitization and awareness generation programmes. For instance, in July 2018 the first ‘Two months certificate course on Mental Health and Behavioural Science’ was started in July 2018. In that batch Seven persons have completed the course. Besides, 282 interns registered in Ashadeep during 2017-2019 under the internship programme of the organization. The interns were from different universities or educational intitute across the country including Gauhati University, TezpurUniversity, Assam University, Banglore University, Tata Institute of Social Sciences, Dibrugarh University, IIT (Guwahati and Chennai) etc.

(Source : Field Survey)

5.4 Prerona: The Spastic Society of Jorhat:

Prerona: The Spastic Society of Jorhat provides services to the disabled persons ranging from early intervention, special education, vocational training, rehabilitation etc. in the Jorhat district of Assam. it also conducts certain awareness programme among parents and other members of the society.

Services of Prerona:

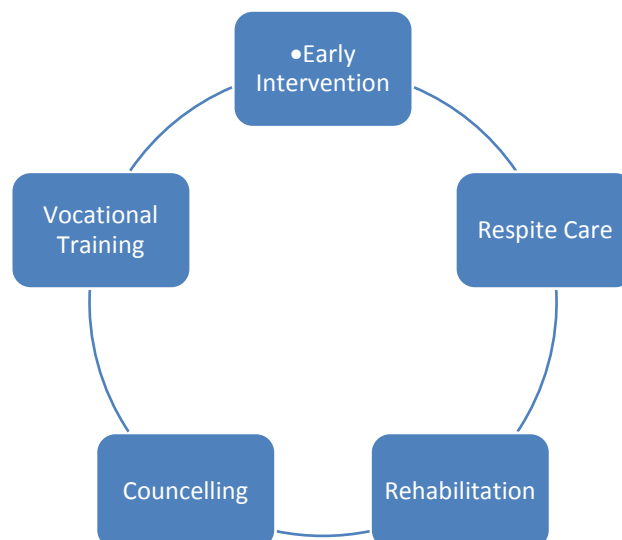


Table 5.7: Organizational structure and staff of Prerona:

Unit	No of Staff
Early Intervention Programme	10
Centre for Special Education	7
Vocational Training Centre	5
Respite Care Centre	7
District Disability Rehabilitation Centre	10
Half way Home for Psycho-Social Rehabilitation of Treated and Controlled for Homeless	5
Community Rehabilitation Programme	12

(Source: Field Survey)

Prerona has been involved with different Government and non-Government agencies for donations/grants, guidance, knowledge sharing, etc. It is the state nodal partner under national trust and it has the affiliation to National Open Schooling and Indian Institute of Cerebral Palsy. The following table shows the list of some of the partners associated with Prerona:

Table 5.8 List of partners of Prerona:

Sl No	Name of the partner
1	Department of Social Welfare, Government of Assam
2	Department of Health, Government of Assam
3	Rehabilitation Council of India
4	Ministry of Social Justice and Empowerment
5	National Trust
6	GiveIndia
7	Indian Institute of Cerebral Palsy
8	Childline
9	National Institute of Open Schooling
10	Blind School, Jorhat

(Source : Field Survey)

5.4.1 Early Intervention Programme:

Early intervention services of Prerona include the children who are at risk or have developmental delays within the age group of 0-3 years. Each and every child receives individualized intervention which includes physiotherapy, speech & language

therapy, child development & family intervention. It is come to know from the field investigation that under this programme 560 children have been benefited up to march 2019. During the time of field investigation 20 children are getting residential care at the organization.

5.4.2 Centre for Special Education:

As mentioned in the Chapter III, Centre for Special Education provides different types of skill and functional training to the children with cerebral palsy, mental retardation, hearing impairment and autism. The centre accommodates the students from the age group 3 to 20 years and is divided into five units. The following table reflects the units of the centre and number of students enrolled each unit during 2017-2018 and 2018-2019:

Table 5.9 Age wise number of Students and activities in different units of Prerona

sl no	Name of the Unit	Age Group	Focus area	Number of Students	
				2017-2018	2018-2019
1	Ankur	Below 6 years	Physiotherapy, Self-helpactivities, socialization, language promotion	9	11
2	Play	6-10 years	Functional areas such as personal, social, academic and recreational activities	4	7
3	Reception	11-14 years	Occupational and domestic skill development	5	8
4	Functional	14-16 years	Preparation for life skill and counselling for adolescent problems	6	7
5	Pre-Vocational	16-20 years	Time management, behaviour with co-worker etc	8	6

(Source: Annual Reports)

5.4.3: Vocational Training Centre:

As mentioned in the Chapter III, vocational training centre caters different skill development training such as embroidery, handicraft, file making etc. The following table shows the different types of training offered by the organization during 2017-2018 and 2018-2019 along with the number of beneficiaries.

Table 5.10: Year wise Types of Training and Number of Beneficiaries in Prerona

Sl no	Name of the training	Number of beneficiaries	
		2017-2018	2018-2019
1	Screen Printing	7	5
2	File Making	19	24
3	Cutting and Embroidery	4	6
4	Craft	4	6
5	Computer	4	7

(Source: Annual Reports)

5.4.4: Respite Care Centre:

Prerona provides residential services for both short term (respite care) and long term (prolonged care) for persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Handicapped residents and are encouraged to extend support to adults and destitute children. In respite care centre during the session 2017-2018, twenty-one residents and in 2018-2019, twenty residents are availing the services.

5.4.5: District Disability Rehabilitation Centre:

As stated in the third chapter, Prerona is the nodal institute of DDRC for Jorhat district. The services and number of beneficiaries under this scheme are given below in tabular form:

Table 5.11 Year wise Beneficiaries and Services offered by DDRC at Prerona

Sl no	Services	No of beneficiaries	
		2017-2018	2018-2019
1	Survey	400	360
2	Physiotherapy	120	100
3	Speech Therapy/ Audiometry	40	37
4	Distribution of Aid and Appliances	20	18
5	Medical Services	309	250
6	Assessment camp	240	257
7	Orientation to teachers and family	100	90
8	Counselling for Guardianship	70	67
9	Awareness camp	100	120

(Source: Field Survey)

5.4.6 Community Rehabilitation Programme:

As mentioned in the Chapter III, the basic objective of community rehabilitation programme is to involve each and every stakeholder of the society in the process of rehabilitation of the disabled children as well disabled adult. Hence, along with counselling at the family level, the programme initiates certain awareness programmes for the community as a whole. The social workers of Prerona regularly visit the villages as well as schools to identify and sensitize the people about the issue of disability. It is come to know from the field investigation that Prerona generally conducts survey in the moth of July to identify disabled children within the community. For the session 2017-18 the survey was done from 9th to 19th July 2017 where 14 disabled children were identified and in 2018-2019 the survey was done from 2nd July to 12th July 2018, where 12 disabled children were identified. It needs to be mentioned here that Prorona targets mainly the tea garden population under community rehabilitation programme and each year it takes five to six villages not only from the Jorhat District but also from the entire upper Assam. Training programmes are also conducted among the school teachers of SSA schools to make aware about inclusive education.ⁱⁱIt is come to know from the

field investigation that in 2017-2018, one week training programme was conducted from 19th to 24th June, 2017 and in the session 2018-2019, the same was conducted from 1st July 2018 to 6th July 2018. As a part of community rehabilitation and in collaboration with district administration, Prerona also distributes certain aids and appliances like wheel chair, roletor, BTE mono, Msied kit, T/C etc. The number of beneficiaries receiving different appliance are given below in tabular form.

Table 5.12: Year wise beneficiaries receiving appliances at Prerona:

Appliances	2017-2018	2018-2019
Wheel chair	4	5
Roletor	3	4
BTE Mono	7	6
Msied Kit	1	0
T/C	5	3

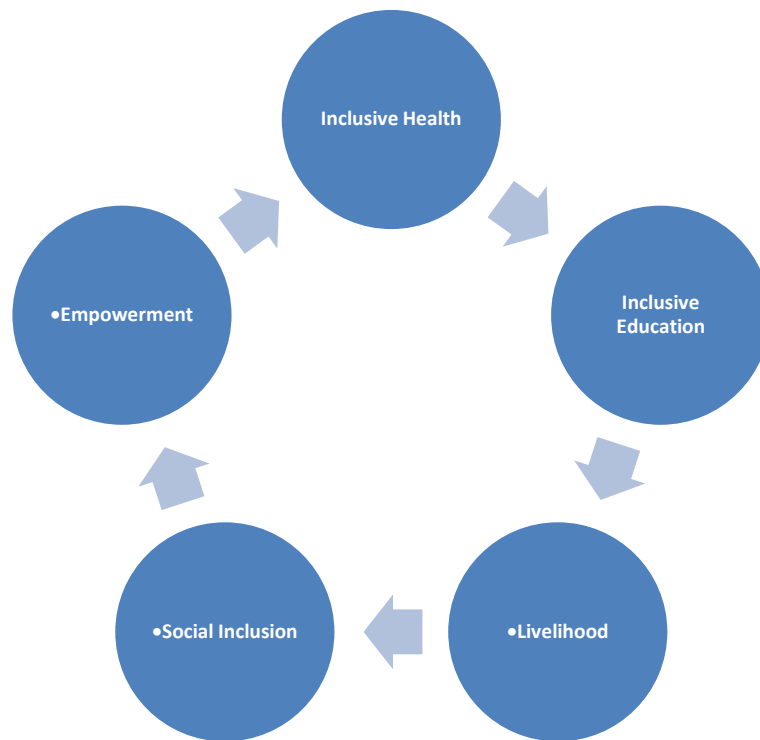
(Source : Field Survey)

It needs to be mentioned here that Prerona also helped the disabled people in getting disability certificates. In 2017-2018, forty persons received disability certificate and whereas in 2018-2019, disability certificates are distributed among thirty-six disabled people.

5.5 Swabalambi: Society for Rehabilitation and Training of Persons with Multiple Disabilities

Swabalambi is CBR organization aims at rehabilitation of disabled persons at community level. The organization covers Dimoria block, Kamrup (Metro) district and ChayaniBarduar Block, Kamrup District (Rural) for holistic development of disabled persons from 0 to 70 years including health, education, livelihood, social inclusion and empowerment.

Services of Swabalambi



Organizational Structure and Staff: As Swabalambi is an NGO basically deals with community-based rehabilitation (CBR) for the persons with disability, no concrete organizational structure is found in it at the time of survey. It employs different officials on contractual basis for a particular time frame to accomplish its projects. However, it consists of following model (mentioned in the Chapter III):

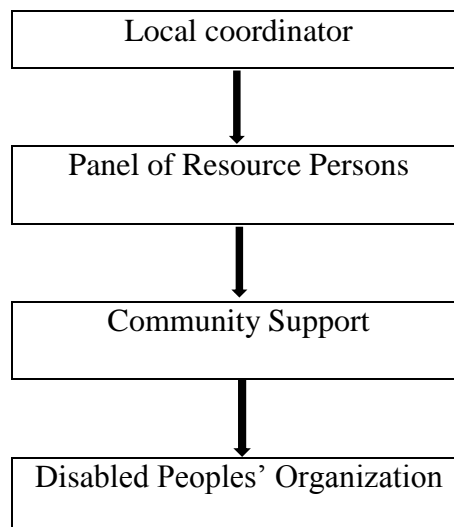


Table 5.13:List of partners of Swabalambi

Sl no	Name
1.	World Bank*
2.	Department of Social welfare, Government of Assam
3.	Department of Health, Government of Assam
4.	Indian Oil Corporation
5.	Numaligarh Refinery Limited
6.	Creative (NGO), Guwahati
7.	Guwahati Eye Hospital
8.	Lions Club, Guwahati
9.	Rang De, Bangalore

(Source : Field Survey)

*CBR network is being sponsored by the World Bank.

The Activities of Swabalambi during June 2017 to June 2019 are given below

(Source: Annual Report)

5.5.1 Promotion of Inclusive Health:

Swabalambi conducts Health Assessment Camp in remote areas and provide free medicine with follow up. For example, the organization facilitates to do cataract surgeries for the elderly population free of cost with the support from Guwahati eye Hospital and in collaboration with the project smile India, the organization also makes arrangement to do plastic surgery of Cleft lip of some of the children. Besides, Swabalambi is the nodal of Assam Government for issue of Disability Certificate in Kamrup(Metro) District and Kamrup (Rural) District. With financial support from Indian Oil Corporation (IOC), Numaligarh Refinery Limited (NRL) and technical support from Artificial Limbs Manufacturing Corporation of India (ALIMCO), Swabalambi has been trying to provide appropriate Aids/Appliances for mobility and hearing to the needy disabled and data shows that almost ninety five percent disabled have received the aids and appliances. As regard people suffering from mental illness and epilepsy, Swabalambi ensures regular check-up and avail proper medicine to prevent

relapse. For identification and early intervention of the children with disabilities, Swabalambi tries to keep a close connection with rural health workers like ASHA workers, doctors and ANMs in PHCs and District Hospital. After identification of disability, the CBR worker of the designated Gram Panchayat starts individual rehabilitation plan with the whole CBR team. The parents and family members are also provided counselling and training on early stimulation exercise for the baby with identified disability. During June 2017-June 2019 Swabalambi facilitated Free Cataract surgery of 29 adults. In collaboration with Guwahati Eye Hospital and Lions Club, Guwahati free high-powered spectacles are also provided to children with Low Vision. During the period of field investigation 748 disabled persons received Disability Certificate from the session 2017-2018 and 1049 PWDs received the same for the session 2018-2019.

5.5.2 Promotion of Inclusive Education:

The CBR programme of Swabalambi tries to ensure the equal participation of children with disabilities in educational institution with other non-disabled children to receive quality education. Therefore, the CBR workers of Swabalambi individually take care of disabled children within their Panchayat and make every possible arrangement in the school for their reasonable accommodation. They try to assist the teachers in the village schools. It is the duty of all CBR workers to ensure that the student with disability get the scholarship for attending school, whereas the other students will receive the same having a good academic record. Training on Inclusive Education for primary and middle School teachers is also conducted by the CBR workers. The basic objective of the training is to make aware of the fact that how a disabled child can be managed in classroom atmosphere. Four training programmes were conducted in 2017-2018 and three training were conducted in the year 2018-2019. Swabalambi has also some CBR Workers who are trained in Indian Sign language and they help the deaf children in the schools. However, they mentioned that the students with disability very often drop out of school after the Class VIII due to lack of trained teachers in special education. However, it needs to be mentioned here that in 2017-2018 and 2018-2019,

total 241 children with disabilities got enrolled in government schools in the two blocks viz. Dimoria and Chayani Barduar.

5.5.3 Livelihood:

One of the basic objectives of Swabalambi is to provide skill development training to all school dropouts, both disabled and non-disabled on locally available resources and are viable at the market. For example, the organisation conducts training to make innovative and advanced design in Bamboo, Jute, Cane and weaving. Tailoring and Crochet design work also taught in line with the branded apparels. Trainings are also conducted on broom grass cultivation/ broom Production, fishery, piggery and poultry. In association with Rang De, Bangalore, a micro finance unit to “Knock Out Poverty” in rural India, the skill artisans are provided small loans to start their enterprises. It needs to be mentioned here that 24 disabled persons and their families received the loan in 2017-2018 and in 2018-2019, 16 families were benefited from the same.

5.5.4 Social Inclusion and Empowerment:

Swabalambi's basic objective is to create a barrier free community including disabled persons with equal human rights. To advocate the rights of the disabled persons and to make cognizant about the different dimensions of disability, Swabalambi has developed groups of disabled persons viz. Disabled People's Organizations (DPOs) at each Panchayat. The skilled members of the DPO try to facilitate different aspects of inclusion of disabled persons in the society. For example, the DPOs initiate for the celebration of International day for Persons with Disabilities every year in their respective block/panchayat level. Swabalambi also pledges for conservation of natural resources. In collaboration with an NGO viz, CREATIVE, it has started a new project called AMAR prithibi Amar Ghar in the year 2017 in Chayani Barduar block of Kamrup District, Assam. In this project some of the selected students from class VIII to XII have been trained on environmental protection and control of air pollution. Tree plantation programmes were also organised once in a year under this project.

5.6 Responses of the NGO workers:

During the course of field investigation, some of the NGO workers were also interviewed to understand the proper functioning of the organisations and as well as government's approach in this regard. Almost all the NGO workers have stated that for smooth functioning of the NGOs in any field requires a support and helping hand from the government machinery. However, the NGO workers have expressed their disappointments about irregular funding as well as inadequate support on the part of the state government of Assam. Besides, they have mentioned about the bureaucratic red-tapism as well as lukewarm attitude of the government to grant fund in the disability sector. Hence, at times many NGOs search for alternative sources like international agencies, private sponsorship, and corporate houses for generating fund. Apart from these, they also emphasize on self-generation of fund by making certain handicrafts, farming, poultry houses and so on. Besides, they have also referred to certain technical issues which may sometimes create obstacles in their functioning. For example, some of the NGOs have conferred the responsibility to fulfil all the procedures for issuing a unique identity card for the disabled persons. They provide supports to the disabled persons for applying unique identity cards issued by the government for getting benefits under certain beneficiary schemes introduced by the government from time to time. However, it has been remarked by the NGO workers that there is a communication gap between the medical practitioners and the legal apparatus pertinent to disability. As a result of which certain issues of non-convergence have been witnessed in some spheres. For example, the RPWD Act emphasized on percentage of disability for issuing disability certificate. The Act has defined people having forty percent and above disability as benchmarked disability. On the other hand, as informed by the NGO workers many health practitioners (doctors) mentioned only the types of disease suffered by a person rather than defining it in terms of percentage of disability. In this regard, it needs to be mentioned here that some of the NGOs are playing a significant role for reducing such gaps. For instance, the Disability Law Unit of Shishu Sarothi organises seminar, workshops in different places of the state particularly in medical and educational institute with support from Social Welfare Department and Disability

Commission, Government of Assam to bring awareness about various legal provisions pertinent to disability and policies introduced by the government.

5.7 Conclusion:

The above discussion reveals the role of NGOs in addressing the issue of disability in the state of Assam. As disability is a multifaceted issue, proper counselling, adequate rehabilitation, medical intervention and human rights advocacy etc. are some of the important dimensions that need to be taken into consideration for developing a comprehensive understanding of the issue. In Assam some of the NGOs are trying to deal with the issue in an inclusive manner. For example, Shishu Sarothi is trying to address the issue of multiple disability starting from early intervention to disability rights advocacy. Similarly, as regard mental disability Ashadeep is taking care of all the different aspects of mental illness as well as mental retardation. However, the role of NGOs in the field of disability in Assam is still in its nascent stage. More proliferation of NGOs as well as systematic intervention by them are needed to deal with the issue of disability in an all-inclusive manner. For instance, field study reveals that the existing NGOs working in the field of disability in Assam are performing their activities only in a limited arena such as mental rehabilitation, early intervention, vocational training, disability advocacy, community-based rehabilitation and so on. There are many issues that are yet to be taken up such as learning disability, professional skills, inclusive education, issues pertinent to other specific disabilities as categorised in the disability legislations. So far as the role of the State is concerned, government still does not have proper planning and systematic approach towards conferring certain responsibilities to the NGOs pertinent to disability. In this regard, overlapping of the work at the functioning level have been noticed during the time of field investigation. For example, government has conferred the responsibility of early intervention to more than two NGOs. However, in respect of community-based rehabilitation, the functioning of the NGOs is very limited. In such a situation, for developing a balanced and inclusive approach, State intervention and proper coordination is needed in a more effective manner.

ⁱThe Sustainable Development Goals (SDGs) or Global Goals were formulated by the United Nations General Assembly in the year 2015 to be achieved by the year 2030. The basic objective of SDGs is to achieve a more sustainable future for all. There are seventeen goals in SDGs, which mainly aim to address the global challenges like poverty, inequality, climate change, environmental degradation, peace and justice (<https://sdgs.un.org/goals> , accessed on 21.03.2021).

ⁱⁱ Inclusive Education refers to the system where all the children irrespective of ability or disability can get education in the same school. Inclusive education is when all students, regardless of any challenges they may have, are placed in age-appropriate general education classes that are in their own neighbourhood schools to receive high-quality instruction, interventions, and supports that enable them to meet success in the core curriculum (Bui, Quirk, Almazan, & Valenti, 2010; Alquraini & Gut, 2012).

CHAPTER VI

CONCLUSION: BASIC FINDINGS AND ALTERNATIVES

6.1 Summing up the Basic Findings:

In the preceding chapters an attempt has been made to examine the role of the state in addressing the issue of disability with special reference to the functioning of different institutions related to the issue of disability in Assam. For that matter, a number of governmental institutions pertinent to disability located in Assam and a few scheme beneficiaries from Kamrup (M) District and Jorhat District were taken into consideration for empirical investigation. In that context, a survey has also been carried out to explore the functioning of some of the non-governmental organizations (NGOs) pertinent to disability. The basic findings of the study are as follows:

a) Disability as an issue of State intervention emerged in the interwar period with the growth of welfarism at the international level. However, it assumed its significance at the policy level in 1990s with the enactment of different State legislations like Americans with Disabilities Act 1990, British Disability Discrimination Act 1995 and so on.

b) While understanding the role of Indian State, it can be said that although equal protection, reasonable accommodation etc are enshrined in Indian constitution, disability as a category of legal intervention was introduced only after 1990s with the enactment of PWD Act 1995. However, a number of legislations like the Medical Termination of Pregnancy Act 1971, the Mental Health Act 1987, the Rehabilitation Council of India Act 1992 etc. were passed at different point of time which are directly or indirectly related to the issue of disability.

c) The institutional arrangements that have been made at different points of time by the Indian State so far are inadequate to deal with the issue of disability in a comprehensive manner because of the multifaceted nature of the problem of disability as well as the complex cultural milieu of the Indian society.

d) In India, the initiatives that have been taken for persons with disability are much more preoccupied with medical and rehabilitation model rather than a social model. The two legislatures viz. PWD Act 1995 and RPWD Act 2016 emphasised on medical parameters of identifying disability. Medical dimension is of course an important part so far as the diagnosis of disability is concerned. However, disability is also a socio-cultural construction that has impacted upon both at the individual and societal level that needs more intervention to unearth those multi-layered construction.

e) Although the constitution of India reflects the commitment of the State's responsibility towards deprived and marginalised categories, over the years it has been witnessed that with the proliferation of the non-governmental organizations the responsibility of the State towards marginalised category like disability has been gradually handed over to non-governmental organizations. Hence, a process of depoliticization has been seen even in the domain of disability as the nascent growth of the disability movements in India have been replaced by NGO activism in the public domain.

f) It has been observed in the study that most of the NGOs are concerned with certain specific types of disability. Although, NGOs interventions play a pivotal role for mainstreaming disability, proper state's intervention and necessary coordination is missing towards addressing the issue from a holistic perspective that overlooks the questions of rights and dignity of the disabled persons.

g) Although the provisions of the PWD Act 1995 and more recently the RPWD Act 2016 have made important contribution for dignity and reasonable accommodation to the disabled persons, both the legislations have overlooked certain issues associated with the problem of disability. For example, in the PWD Act 1995 certain categories of disability like 'deaf-blind', 'HIV/AIDS leading to disability', 'colour blind' etc are not included. On the other hand, the RPWD Act 2016 has made certain micro-categories of disability including total twenty-one types of disability. However, at the grassroot level particularly at the district level hospitals in Assam no special arrangement has been made for identification or categorization of 'new' disabilities as mentioned in the legislation.

h) The disability affair in the state of Assam is bestowed upon two government departments viz., the Social Welfare Department and the Health Department. The Health Department identifies the level of disability and the Social Welfare Department implements certain policies and programmes pertinent to disability. Hence, the whole disability affair is dominated by bureaucratic and medical approach, which is not enough to deal with psycho-social dimension of disabled people.

i) In the state of Assam, a number of schemes have been introduced from time to time pertinent to disability. However, at times those schemes have failed to touch upon the disabled people living in the remote and rural localities. Most of the schemes are designed for a short span of time and execution of those schemes totally depend upon the routine works of the government departments rather than having any social commitment for overall upliftment of disabled persons. For getting the benefits under a particular scheme a disabled person has to do many formalities which itself becomes challenge for him/her. Hence, it reflects the piecemeal approach of the State towards addressing the issue of disability.

j) The techno-bureaucratic approach of the State is very much prevailing even in the disability sector too. For example, recently the Government of India has initiated the provision of unique identity card for disabled persons which requires online submission of the documents of the person concern. However, the field investigation reveals that disabled persons having different types of disability like blindness, learning disability, mental disorder and so on are not in a position to accomplish those formalities. In such a situation it can be conclude that the State is adopting a top-down approach rather than a bottom-up model to address the complex issue like disability.

k) The study also reveals that while formulating policies by the State, proper coordination is missing among the different departments of the Government. For instance, the legislations pertaining to disability in India are talking about a barrier free environment in public places for disabled people. However, for that proper coordination among different departments like transport, public works department, education etc are needed.

6.2 In Search of Alternatives:

The basic objective of conducting an academic research work is to generate new knowledge in a particular field of study. An academic study becomes relevant once it provides certain remedies and alternatives for smooth functioning of a system for the future policy makers. Disability as an area of academic investigation particularly in the state of Assam is of course a new field that requires further research for better understanding of the issue. During the course of the present study, many lacunas or shortcomings have been witnessed that needs more intervention by the State or other agencies for the better working of the system. Keeping this point in mind a few recommendations have been made here that may be helpful for the process of future policy formulation in the field of disability:

a) The Schemes of the government pertinent to disability should be category specific rather than general in nature. Although disability is a holistic category, the micro-categorisation within itself requires different needs and assistance. For example, the requirement of a locomotor disabled person may not be similar with a blind person. For that matter disability specific policies may benefit the disabled persons in substantial manner.

b) For the governance of the issue of disability proper identification is necessary by the State machinery. In Assam the identification of disabled persons is vested on two State departments viz. Social Welfare Department and Health Department. For that matter, the Social Welfare Department organises health camps from time to time and sometimes confers responsibility to some NGOs. However, it was witnessed during the field investigation that sometimes the medical terminologies that have been used by the doctors to identify a particular disability may not match with the legal terminologies that are enumerated in the legislations like PWD Act 1995 and RPWD Act 2016. Hence, the doctors those who are associated with the identification of the disability should be given certain orientation and training so that there will be coordination between legal and medical dimension of disability. Besides, more pro-active role of the State is required for identification of the disabled person by deputing certain officials for door to door visit to collect data regarding disabled persons.

c) It needs to be mentioned here that the RPWD Act 2016 has made twenty-one micro categories of disabilities based on certain medical conditions. However, the field investigation reveals that the district hospitals of Assam are lacking proper medical infrastructure and experts for identifying these micro categories of disability as mentioned in the legislature. In such a situation the disable persons remain unidentified in most of the districts of Assam excepts the districts having medical college hospitals. Therefore, the government should make appropriate steps to arrange proper infrastructure and experts in each and every district of Assam.

d) One of the important initiatives of the Government of India in accordance with the provisions of PWD Act 1995 in the field of disability is to create a barrier free environment. Accordingly, the Ministry of Urban Development, Government of India has prepared Harmonised Guidelines and space Standards for Barrier Free Built Environment for Persons with Disability and Elderly Persons in February 2016ⁱ that to be followed by every government department both central and the state. However, to create a barrier free environment in public places for the disabled people various government departments like transportation, building, roads etc should work together. Besides, the state governments do not have budgetary allocation to do the needful for the creation of a barrier free environment. Hence, there should be special arrangement for coordination among different departments of the government and budgetary allocation for creating a barrier free environment for the disabled people.

e) As mentioned in the Chapter I, one of the important causes of disability in the developing countries including India is malnutrition and lack of proper care at prenatal stage. It needs to be mentioned here that some of the genetic disorders that cause primary disabilities can be controlled by proper vaccination at prenatal as well as neo-natal stages. Therefore, the government should initiate more such programmes of immunization for reducing disability at primary level.

f) The state Disability Commissioner is a very significant office for the protection of the rights of the disabled person. It is observed in the present study that the state Disability Commissioners in Assam are appointed from the cadre of Assam Public Service Commission (APSC) on routine promotion basis. Generally, a civil servant cadre holds the post of state Disability Commissioner for two to three years in the

middle point of his/her career. At times, the people who hold such a significant office may not have much experience and proper training in the field of disability. Hence, it can be recommended that rather than confining the portfolio only to the civil servants' cadres it can be opened up to those persons who have tremendous experience in the field of disability such as NGO activists, academicians, lawyers and others who gathered proper knowledge and experience in this field.

g) For the comprehensive understanding of the issue of disability, proper research and academic works should be carried out in the concerned field. In contemporary time disability studies has become an emerging area of research throughout the world. However, in the state of Assam the research in the field of disability is very much limited. Only the Gauhati University, a state university of Assam is having a Department on Disability Studies which is still in the nascent stage. Hence, the Government should give attention on both research on disability as well as to make necessary arrangements for educating persons with disability.

h) Rural urban disparity in Indian society is a common phenomenon in all developmental issues. The issues pertinent to disability is also not exception to it. It has been observed in the present study that most of the institutions related to disability are located in the urban centres and the urban disables are more accessible to different schemes and policies of the government. Moreover, the people living in the rural areas are less aware about the rights of the disabled people and policies of the government pertinent to disability. In this regard, Government should initiate some special policies addressing the disabled population living in the rural areas. Besides, for the sensitization of the rural people certain awareness programme should be initiated by the state through mass media. NGOs working in the field of disability should entrusted with such task.

i) Community Based Rehabilitation is one of the most effective method for the empowerment and participation of disabled people in the society as in this method basic emphasis is given on the involvement of the whole community in the process. However, in Assam both Government institutions and non-government organizations till now have not given much emphasis on such initiatives. Hence, it can be recommended that government should promote such initiatives for mainstreaming disabled people in the society.

6.3: Suggested Areas for Further Research:

The findings of the current study are very much confined in nature as the focus is only to study the functioning of the institutions pertinent to disability while exploring the role of the State in this regard. As the study is very much preliminary in the sense that very few empirical works have been done on the issue of disability in the state of Assam. Hence, the study cannot be considered as a conclusive one rather it is just a beginning in the concerned field in Assam. To validate the findings of the present study, some of the areas directly or indirectly linked with the topic need to be researched in the days to come. Some important areas may be the topic for comprehensive research are as follows:

- a) Detailed Investigation of Different Policies of Government of India relating to the Issue of Disability.
- b) Comprehensive investigation of the implementation of Inclusive Education in Assam.
- c) Comparative Analysis of PWD Act 1995 and RPWD Act 2016.
- d) Detailed Investigation of the position of disabled persons in different population surveys of Government of India.
- e) Detailed investigation of the role of Community Based Rehabilitation in empowering disabled people.
- f) Documentation and Research on gender dimension of disability in Assam.
- g) Comprehensive documentation of impact of different policies pertaining to mental disabilities in Assam.
- h) Comprehensive research on poverty, healthcare and disability.
- i) Comprehensive research on role of NGOs and disability.
- j) Detailed investigation of the early intervention programme of the State in eliminate disability.
- k) Comprehensive research on the status of disabled people in rural areas of Assam.
- l) Detailed investigation of barrier free environment in public offices of Assam.
- m) Detailed investigation of rehabilitation approach of the State in the field of Disability.

- n) Comprehensive research on role of the State in ensuring disability rights with special reference to Assam.
- o) Comprehensive research on role of disability rights movement in addressing the issues related with disability in public platform.
- p) Comprehensive research on role of mass media in sensitizing the people about the issue of disability in Assam.

6.4 Role of the State in Disability: A Critical Appraisal

The present study has provided an overview of the functioning of the institutions/organizations pertinent to disability in the state of Assam. An attempt has been made to understand the role of the State in disability in terms of the functioning of the institutions as the State machinery performs its role through the operationalisation of its institutions. After the achievement of independence, India adopted welfare model through its constitutional vision by providing certain social security measures to the downtrodden sections of the society. However, in the initial years after independence disability as an issue did not assumed significance in the political discourse. Although India emerged as a strong developmental State in the post-colonial phase of its history, disability as an issue of State intervention has not been prioritised at the policy level till 1990s. Due to certain international developments and a global consciousness that emerged in different parts of the world, India also started adopting certain policies, legislations and institutions pertinent to disability in 1990s. At the same time, 1990 was the decade which was also marked by the acceleration of the process of globalization that paved the way for the emergence of a neo-liberal State where the State's responsibilities have been conferred to other non-state actors like NGOs, multinational corporations, transnational organizations etc. In such a situation, in the field of disability a gradual shift has been noticed from welfare model to right based model with the adoption of new disability legislations and proliferation of NGOs for advocating disability rights. India in contemporary time, being a signatory of the UNCRPD 2006 had replaced its earlier disability legislation i.e., PWD Act 1995 and adopted a more right based and social model centric approach with the enactment of the RPWD Act 2016. The issue of disability in present day context has also become a populist policy

issue with the formulations of a number of policies and schemes by using popular nomenclature like *Divyanga* (people with divine organ) for persons with disability by the Indian government. Assam, being a constituent state of the Indian Union is also not an exception to those developments. Hence, while examining the role of the State, it can be said that in contemporary time the Indian State is in its critical juncture where the legal apparatus or the disability legislation is emphasizing on a more right based approach, the political apparatus i.e., the government is emphasizing on populist beneficiary schemes with a charitable approach. In such a situation, the role of the State in disability in Indian context is at the crossroad while a divergence has been noticed between the political and the legal apparatus of the State. Due to the lack of proper convergence between the legal discourse and the political orientation, Indian State still could not come out with a proper roadmap for the future to deal with a highly complex issue like disability.

ⁱHarmonised Guidelines and Space Standards for Barrier Free Built Environment for Persons with Disability and Elderly Persons was launched by the Ministry of Urban Development in February 2016. The basic objective of the guidelines is to provide a practical framework for inclusive and accessible design of public and private spaces. The guidelines build over the existing manuals such as Guidelines and Space Standards for barrier free built environment for disabled and Elderly Persons, CPWD, 1998, Manual on Barrier Free Environment, MSJE, 2002 and National Building Code, Bureau of Indian Standards, 2005. See detail *Harmonised Guidelines and Space Standards for Barrier Free Built Environment for Persons with Disability and Elderly Persons*, Ministry of Urban Development, Government of India, February 2016.

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Annexure:I

Interview Schedule for the Beneficiaries of Rehabilitation Grant:

1. Name:
2. Age group
3. Annual Family Income:
4. Educational qualification:
5. How did you get the disability certificate?
6. Did you find any problem in the process of getting disability certificate?
7. Do you satisfied with the process of getting disability certificate?
 - a) If no, give your suggestion.
8. How do you know about the scheme?
9. Do you find any problem while applying for the grant?
10. Did you avail any other facilities apart from this rehabilitation grant?
 - a) If yes, specify.
11. Are you involved with any disability organization?
 - a) If yes, how?

Annexure:II

**Interview Schedule for Student Beneficiaries of Medical and
Technical Education**

1. Name:.....
2. Institution:.....
3. Permanent address.....
4. Types of disability and percentage.....
5. When did you apply for the disability certificate?.....
6. Educational qualification.....
7. Income of the concerned individual (If any):.....
8. Income of the family.....
9. Please mention whether enrolled under:
 - I. Merit
 - II. Disability Reservation Category
 - III. Other Reservation

10. Please mention whether received any other benefits other than the scholarship from Social Welfare Department, Government of Assam:.....
11. Do you think the schemes like the present one is really beneficial for you? If not why?
12. Have you found the environment of the present institute is disabled friendly or not?
If yes how.....
If not, why?.....
13. What are the special arrangements for persons with disability in your institute?
 - a)
 - b)
 - c)
 - d)
 - e)
 - f)

14. Would you like to advice to make your institute more disable friendly.....
.....
.....
.....

15. Have you heard about new RPWD Act 2016?
.....
.....
