

Service for Multi-Disabilities and Visual Impairment (MDVI) in Nepal

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Background:

1. Services for PWDs

a. Education: Nepal started educational services for PWDs in sixties. The then college of Education with the support of Ministry of Education (MOE) started a cooperative type of Integrated Education program for Children with Visual Impairment (CVI) at its Demonstration School known as Laboratory School in Kirtipur, Kathmandu in 1964. A school for the deaf was started in the premise of Bal Mandir (a government authorized institution to take care of Orphan children) Naxal in Kathmandu in 1966. Educational facilities were available only for fortunate children in a very limited number for many years. MOE established Special Education Council (SEC) to support and look after education of PWDs in 1974.

Basic and Primary Education Project/Program (BPEP I & II) was implemented by government to all primary level children from 1993. Under BPEP government started integrated units for children with visual hearing and intellectual impairments in regular primary schools through out the country. It can be taken as a major educational thrust for Children with disabilities (CWDs) despite of sporadic educational services provided by NGOs and SEC at snail pace. Presently, more than 13, 000 CWDs are receiving school level education through 330 resource centers of BPEP and schools run by NGOs.

b. Rehabilitation: Process of rehabilitation through legal provision began after the promulgation of first National Civil Code in 1853. The National Civil Code under the heading of Garib *Kangal* mentions that, “Disabled people who are not able to work

and earn their livelihood were entitled to receive shelter, food and two pairs of garments every year.” However, it was not found practically implemented due to various reasons.

A visionary Late Khagendra Basnyat a physically disabled person started process of rehabilitation through NGO only from 1969 after the establishment of a first NGO Nepal Disabled and Blind Association (NDBA) in Kathmandu. NDBA, that renamed itself as NDA limited its services only for persons with locomotive/mobility impairment. NDA provides institution based education and vocational training apart from CBR program.

c. Handicapped/Health Services Coordination Committee (HSCC): HSCC was constituted under Social Service National Coordination Council (SSNCC) established in 1977 by the Government to provide rehabilitation services to all PWDs and to facilitate NGOs that work for social services in the country. SSNCC is functioning as Social Welfare Council but it has no committee like HSCC concerned with disability. However, HSCC was instrumental in coordinating INGOs and supporting all NGOs working for PWDs till 1990.

2. The International Year of Disabled Persons (IYDP)-1981

It was IYDP-1981 that drew the attention of government to wards education and rehabilitation of PWDs in the country. The major out comes that Nepal achieved by observing the IYDP-1981 apart from sensitization can be taken as,

- a. Sample Survey on Disability was carried out in 1980, which projected 3% as the population of PWDs.
- b. Establishment of Disabled Relief Fund (DRF), which started to provide scholarship and vocational training to PWDs since 1981.
- c. Creation of an environment to establish NGOs for PWDs.

3. Establishment of NGOs

a. A Center for the welfare of the Blind started its activities under NDBA since 1982, which latter renamed as Nepal Association for the Welfare of Blind (NAWB) in 1985. Welfare Society for Hearing Impairment (WSHI) and Association for the Welfare of Mentally Retarded (AWMR) were established in 1984 in 1985 respectively. These NGOs have been providing welfare-based services to PWDs in different parts of the country.

b. Emergence of Self Help Organizations (SHOs)

SHOs were allowed to form their organizations only from 1990. Many SHOs came into existence like Kathmandu Association of Deaf (KAD), Nepal Association of Blind, National Federation of Disabled-Nepal (NFD-N) and Federations of Deaf persons, Organizations of Locomotive and Mobility Impairments and many other SHOs including Parent's organizations were established from 1990 to 1995. According to NFD-N there are more than 152 affiliated SHOs under its umbrella. These SHOs have been instrumental in pressurizing government to adhere with rights based approach and playing crucial roles in improving the quality of lives of stakeholders.

4. Prevalence of Disability

The prevalence rates of PWDs as shown by various studies conducted by different agencies from 1971 to 2001 greatly vary from 0.45 to 8.99% in Nepal. Therefore, NFD-N follows WHO estimation of 10% as population of PWDs in Nepal. Regarding Multi-Disabilities and Visual Impairment (MDVI) no survey has been conducted focusing on it.

The first sample survey on disability has reflected 11.9% as the population of Multi-Disabilities out of 3% population of PWDs. A survey conducted by a government agency has revealed .51% population as Multi Disabilities out of 1.63% disabled population as reflected. (However, the figure has strongly been objected by NFD-N and other SHOs including professionals.) The variation happened due to non-uniformity in adopting definition of PWDs by agencies while conducting the surveys.

5. Service for MDVI

Ms. Sabitri who lost speech, hearing and sight at the age of eight due to typhoid was the first known case to receive rehabilitation service in NDBA During 1970-1980. She learnt knitting, weaving and palm reading in NDBA. She spent whole life there as none of the family member turned out to take her home.

The rehabilitation service for MDVI is a new start in Nepal. A modest beginning was started from late 1995 only. The writer with a motivation received by a British volunteer Ms. Susana Gibson (referred by Mrs. Dale Davis who worked for Helen Keller International in Nepal) who met a deaf blind girl in a village of Kathmandu during her field visit to screen the street children. Writer started home visit program during weekend and public holidays, as there was no organization that take care of such children.

MDVI were and are referred to writer by Staff of NAWB, friends of teaching hospitals, resource teachers and volunteers. Writer with his friends' audiologist and speech pathologist, Physiotherapist and teachers from Ankur Vidyashram continue home visit to four MDVI children. When the number of MDVI referred reached to 14 the writer faced difficulty in carrying out home visit even during weekend. In such difficult condition Ankur Vidyashram has come out to extend its support from 1995 to continue the activities as out reach program of School. Presently, 21 MDVI are under valley CBR run by AFINED.

6. Establishment of Ankur Foundation for Inclusive education (AFINED)

The increased number of MDVI encouraged writer to establish an NGO, AFINED with likeminded professionals and social workers in June 1997 as a first organization to work in the field of Deaf blind and Multiple-Disabilities and in special needs children in an inclusive way. Fortunately, writer came into contact with the officials of Hilton/Perkins Program of Perkins School for the Blind who visited MDVI field activities in Nepal and extended support in human resource development and CBR program since September 2001.

Bhaktapur CBR has also started CBR program for Multiple-Disabilities since 1995 within Bhaktapur District. WSHI with the support of DSI (Danish Federation of Disabled) has opened a Deaf blind unit at School for the Deaf Naxal in November 2005. 4 Deafblind children identified by Valley CBR, program of AFINED have opportunity to get enrollment. Presently, four Deafblind children are placed at the first phase. Mrs. Lone Poggioni from Parents Association of Deafblind, Denmark and Ms. Ignore Rod bore were instrumental to open the unit. AFINED will refer suitable Deafblind children to School for the Deaf in future too.

7. The recent trend of education and rehabilitation for PWDs

The recent trend for educating and rehabilitating PWDs is shifting from segregated to integrated and to inclusiveness. The traditional concept of viewing PWDs through welfare-based approach has been changed towards Human Rights approach.

The IYDP-1981 with its slogan "Full Participation and Equality" has opened the inclusive door to PWDs in all sectors of society including the education. Salamanca Conference has further emphasized inclusive Education in 1994. Department of Education, Inclusive Education Section has initiated rights based approach in educating CWDs through 210 inclusive classes of 22 of 75 districts.

A Joint Position Paper produced by International Labor Organization (ILO), United Nation Educational, Scientific Cultural organization (UNESCO) and World Health Organization (WHO) in 1994 has emphasized the CBR approach *especially for*

those with the least access include women with disabilities, people with severe and multiple disabilities, people with psychiatric condition, people living with HIV persons with disabilities who are poor and their families.

According to Dr. E. Helander, “CBR seeks integration of the interventions of all relevant sectors educational, health, legislative, social and vocational and aims at the full representation and empowerment of disabled people, promotes interventions in the general system of society, and adaptations of the physical, psychological environment that will facilitate the social integration and the selfactualisation of disabled people.”

The UN Standard Rules has also emphasized that; “All rehabilitation services should available in the local community where the person with disabilities lives” Having all these international instruments, guidelines and the experiences gained in the field of Blindness and Deafness AFINED has planned to heading towards developing and running inclusive education and CBR program for MDVI and for other special needs children as far as practicable in the Nepalese context. 4 out of 21 MDVI are Placed in inclusive classes. 4 other children got opportunity to enroll in the deaf blind unit of School for the Deaf, Naxal. Major NGOs working for PWDs, SHOs and Ministry of Women, Children and Social welfare (MWCSW) have major focus on CBR Program for PWDs.

8. Human Resource development

AFINED had one resource teacher trained in Helen Keller Institute of Deafblind, Mumbai and one more teacher is undergoing training in the same institute. In order to aware and sensitize on teaching/learning process for MDVI basic training for two days were organized two times in 2005 for 40 government and NGO teachers working for the children with visual, hearing and intellectual impairment in 10 Districts. Similar type of training will be organized for another group of 40 teachers in 10 additional districts to create environment for inclusive education and CBR program for MDVI. AFINED has supported to form parents groups for their participation in day-to-day activities of their respective MDVI.

9. Some challenges

Parents do not believe that MDVI children can be educated and rehabilitated. NGOs find difficult to convince government officials to formulate policy and plans on rights basis for MDVI, as it has been a neglected area. NGOs are facing difficulty in mobilizing internal resources due to conflict, insurgency and poverty. It has led difficulty for timely expansion of CBR and inclusive program in rural areas. Lack of human and other resources play vital roles to strengthen the program. CBR staff and professionals find difficulty in showing quick results as per the expectation of parents due to non-availability of local materials and appropriate

service/counseling center. It is difficult in providing training to teachers, CBR workers, volunteers and parents at different levels due to lack of training centers and manpowers. These are some burning challenges always remained as barriers during implementation of the program at various stages.

10. Problems /Issues/Barriers

There are numbers of problems/issues/barriers that hinders to run program effectively. Some major problems are highlighted here,

- a. Attitudinal barriers (from community, family members and friends),
- b. Lack of legislative provision
- c. Lack of definition
- d. The poor condition of livelihoods
- e. The extra burden for parents due to DbP/MD children in family
- f. Not finding family support to care such children
- g. The heavy workload to solve their hand to mouth problem
- h. Exclusion from social and cultural activities for having MDVI children
- i. Mothers are victimized by family members for having such children
- j. No referral places for information and training of children
- k. No counseling and training center for parents
- l. Lack of awareness among common people
- m. Lack of trained human resources (professionals and CBR workers) to tackle with the children

11. Need:

In order to promote inclusive education and provide rehabilitation services through CBR approach AFINED as felt and experienced some needs that have to be addressed are as follows,

- Organize awareness campaign in communities involving parents/family members, neighbors and among professionals to remove prevailing social taboos and negative attitude towards MDVI.
- Provide opportunity for social mix-up to parents to talk freely about their children and participate in social and cultural activities to reduce exclusion.

- Organize training (short and long term) to develop human resource at different levels (teachers, CBR workers, parents and volunteers) to run education and CBR programs.
- Establish training center for children and their parents for skill-based training including concept development, activities of daily living, socialization, and rehabilitation for short period.
- Involve parents /family members in therapeutic, occupational and training in other developmental aspects that are deemed necessary for the balanced growth of MDVI children and adults.
- Provide of medical, psychological and therapeutic services with nutritious food as necessary to ensure children's health to maintain basic physical fitness that require to develop mobility and learn other basic skills for possible independence.
- Offer income-generating programs to needy parents/family members to allow more time to take care of their respective children.
- Support in strengthening teachers, parents and volunteers group to work towards the rights and interest of MDVI children, youth and adult for the wider inclusion in families and communities through CBR approach by creating barrier free environment in society.
- Organize orientation to government agencies to develop policy, plan with legislative provision to ensure the rights of MDVI
- Organize awareness seminar/workshop to mass media to remove negative attitude from the society and to pressurize government agencies to formulate policy, plan and legislation as required to ensure social security and rights to live with dignity in families and in communities.

12. Recommendations

- ICEVI as an International forum of professionals should formulate a policy coordinating with concerned agencies and organizations and develop action plan to benefit MDVI globally with focus on developing countries.
- Develop strategy to support manpower and materials development training.
- INGOS should support in establishing training centers to facilitate training to teachers and CBR workers of developing countries.

13. Conclusion

Despite many challenges and barriers Inclusiveness demands rights based approach in every walk of life. CBR respects disabilities and differences and provides equal opportunities to participate in activities and access without discriminations. Therefore, AFINED is moving towards promoting inclusive education coordinating government and private schools and expanding CBR program through out the country. Professionals and parents will be involved in carrying out activities concerning MDVI children, youth and adult for their benefit. CBR approach is forward looking with sustainable point of view. CBR is affordable and accessible to all. Receiving comprehensive CBR is the rights of MDVI. Let us develop and an inclusive society with barrier free environment to MDVI wherever they live.

Let International NGOs/Development partners extend their cooperative hands to organizations working for the development of MDVI who are living below human dignity especially in rural and remote areas of developing countries.

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